

Client-Centred Care in the Canadian

Home and Community Sector:

A Review of Key Concepts

FINAL REPORT

September 2011



ACKNOWLEDGEMENTS

The Saint Elizabeth project team would like to thank the members of the National Advisory Committee, whose commitment, support and guidance throughout this project were invaluable:

- The Canadian Health Services Research Foundation
- Carol McWilliam, Professor, School of Nursing at the University of Western Ontario
- Cheryl Cott, Professor, Department of Physical Therapy at the University of Toronto
- Kathy Kastner, Founder and President of Ability 4 Life
- Kevin Reel, Ethicist, Occupational Therapist, Southlake Regional Health Centre and York Central Hospital
- Nadine Henningsen, President Canadian Caregiver Coalition and Executive Director, Canadian Home Care Association
- Sherry Dupuis, Director, Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo
- Vaughan Glover, Founder and CEO of Canadian Association for People-Centred Health

Production of this report has been made possible through a financial contribution from Health Canada.

*The views expressed herein do not necessarily represent the views of Health Canada.

This report was prepared by:

Dr. Catherine Brookman, Laura Jakob, Julie DeCicco and Danielle Bender Saint Elizabeth
90 Allstate Parkway, Suite 300
Markham, Ontario, L3R 6H3
research@saintelizabeth.com
www.saintelizabeth.com



Table of Contents

1. INTRODUCTION	
2. METHODOLOGY 2.1 Scope	8
2.2 Definitions of terms to inform the scope of this review	9
3. THE CANADIAN CONTEXT 3.1 Client-centred care in Canadian healthcare policy	1(10
3.2 Provincial and Territorial policy	11
3.3 Professional healthcare policy	13
3.4 Home and community care in Canada	15
3.5 Uniqueness of client-centred care in the home and community sector	17
4. WHAT IS CLIENT-CENTRED CARE AND HOW IS IT DEFINED? 4.1 Background	19 19
4.2 Conceptualizations of client-centred care across healthcare disciplines	19
4.3 Client-centred care terminology	21
4.4 Client definitions of client-centred care	24
4.5 Central themes of client-centred care	28
5. APPROACHES TO THE IMPLEMENTATION OF CLIENT- CENTRED CARE 5.1 Theoretical Models	2 9
5.2 Service Delivery Models	35
5.3 Cognitive approaches to implementing principles of client-centred care	40



6.	. CONCEPTS RELATED TO CLIENT-CENTRED CARE AND THEIR OPERATIONALIZATION 6.1 Power	41 41
	6.2 Empowerment	43
	6.3 Respect	44
	6.4 Communication	47
	6.5 Transitions and continuity of care	53
	6.6 Client participation in care	54
7.	TECHNOLOGY AND CLIENT-CENTRED CARE 7.1 Client engagement and empowerment through technology	65 65
	7.2 Potential of technology to facilitate client-centred care	65
	7.3 Chronic disease management	66
	7.4 Telehealth	66
	7.5 Barriers to the use and implementation of information systems (IS) and technology	69
	7.6 Electronic health record (EHR)	70
8.	. EVIDENCE-INFORMED IMPLEMENTATION STRATEGIES FOR CLIENT-CENTRED CARE 8.1 Individual/Point of care level	71 71
	8.2 Organizational level	78
	8.3 System level	81
	8.4 The home and community sector	84
9.	. MEASURING CLIENT-CENTRED CARE 9.1 Considerations for measuring client-centred care outcomes	<mark>89</mark> 89
	9.2 Methods of measuring client-centred care	90
	9.3 Tools used to measure client-centred care in the home and community sector	93
1(0. CONCLUSION	97



1. INTRODUCTION

Current challenges facing the Canadian healthcare system are significant. An aging population, increasing rates of chronic disease and the high cost of healthcare are forcing healthcare professionals, managers and policy makers to examine how healthcare can best be provided to Canadians.

One noticeable variation in recent years is the increasing role of home and community care, as healthcare provision shifts from the institution to the community (Cott, Falter, Gignac & Badley, 2008; Huvane, 2008; Oudshoorn, Ward-Griffin, & McWilliam, 2007; Romanow, 2002; Woodward, Abelson, Tedford & Hutchison, 2004). The Romanow Report (2002), recognized the importance of home care and acknowledged it as "one of the fastest growing components of the health care system" (pg. 171). This pattern of growth, which is likely to continue, is supported by shifting demographics towards an aging population, increased levels of chronic disease, greater ability to receive care in the home (due to technical and medical innovations), the need to reduce and contain costs, and feedback from Canadians indicating that they prefer to receive their care at home (Canadian Institute for Health Information (CIHI), 2007; Gantert, McWilliam, Ward-Griffin & Allen, 2008; Huvane, 2008; MacAdam, 2004; McGarry, 2009).

At the same time, there is growing support for a change to the overall framework of the system, from a provider-centred model to one which 'puts the client at the centre' of the healthcare system. This model of care, known as 'client-centred care,' is receiving increased attention both across Canada and on the global stage, and is endorsed by the public who are increasingly advocating for their rights as participants in healthcare, rather than being passive recipients of it (Ball, 2010; Glover, 2005). Stakeholders, including politicians, health policy-makers, and healthcare providers, are seeking strategies to address poor satisfaction with healthcare services (Ball, 2010), while at the same time developing efficient, effective and safe models of healthcare delivery that meet the needs of the population (Canadian Medical Association, 2010).

Although there is much discussion supporting client-centred care, there is a lack of clarity or agreement regarding what is meant by the term and how it can be applied in practice (Cott, 2004; de Haes, 2006; Hobbs, 2009; Robinson, Callister, Berry, & Dearing, 2008). Terminology such as patient/client/family/person-centred, patient-focused, person-oriented and client-oriented care are used to describe various systems and approaches to practice (Cott, 2004; DiLollo & Favreau, 2010; Edvardsson & Innes, 2010; Edvardsson, Winblad & Sandman, 2008).

Although these terms are, at times, used interchangeably with client-centred care, closer analysis of the terminology has revealed distinctions between these definitions and how they are interpreted and implemented in practice (Cott, 2004; Hobbs, 2009). As a result of this lack of clarity, practice and implementation of client-centred care has varied between disciplines and across clinical settings.



This is particularly relevant within the home and community context where a variety of healthcare professionals provide care in a multi-cultural, multi-disciplinary environment. The concept of client-centred care has been studied most thoroughly in an acute care setting; however, not all of the approaches, definitions and interventions used in this setting are relevant, appropriate for use or transferable to the home and community care context. The home and community care environment provides a unique lens from which client-centred care can be viewed and enacted, presenting both challenges and opportunities (Litchfield & MacDougall, 2002; McGarry, 2009; Restall & Ripat, 2008).

This Literature Review seeks to examine the available literature on client-centred care within the context of the home and community care sector, clarifying existing definitions, concepts and practices which can influence client-centred care in this environment.

The specific questions considered while conducting this review include:

- How is client-centred care defined?
- What are the key concepts and practices of client-centred care?
- What models of client-centred care have been used in the home and community care context?
- How can client-centred care be implemented?
- What barriers are there to this implementation?
- How can client-centred care be evaluated in the home and community context?



2. METHODOLOGY

This Literature Review is one component of a broader project titled "Client-Centred Care: Future Directions for Policy and Practice in Home and Community Care." The definitions, search strategy and outcomes of this review have been conducted under the auspices of this project using the term client-centred care as the primary focus of the literature review. Upon further consultation with key experts in the area, once the review was completed, the term person-centred care emerged as the most reflective of this holistic approach to healthcare, as it acknowledges the personhood of the individual outside the clinical domain. Although the term 'person' is preferred to 'client', for editorial reasons and to suit the home and community context in which the latter term is most commonly used, this review will primarily use 'client.'

Incorporating published and unpublished literature, this review includes research articles, government policies and other key papers illustrating practices in client-centred care within and beyond the home and community care sector. Key stakeholders also assisted with identifying relevant documents, both nationally and internationally.

A literature search of key databases was undertaken, including MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PubMed. Relevant search terms were identified and refined throughout the literature review process to ensure that the most appropriate and credible reference material was sourced. A staged approach was used, including an initial search to obtain appropriate keywords and subject listings, a full search and a subsequent search of reference lists to identify additional relevant documents. A search of the internet was conducted using Google to find grey literature relating to client-centred care in the home and community sector. A further search of Provincial Government websites was undertaken to identify relevant government reports and policies for inclusion.

Search terms used in the Literature Review included: 'patient-centred care,' 'client-centred care,' 'family-centred care,' 'person-centred care' and 'relationship-centred care,' and these were combined with search terms 'home care,' 'home care services,' 'community services' and 'community health services.'

The lack of consensus regarding the definition of client-centred care made the search for literature difficult, as did the fact that the definition of client-centred care used for this project was broader than some of the definitions studied in the literature. Additional searches were therefore conducted to complement the client-centred care literature, using the search terms: 'patient partnerships,' 'patient engagement' and 'patient participation.'

-

¹ Funded through a financial contribution from Health Canada.



All literature identified during the database search was assessed for relevance to the review based on the information provided in the title, abstract and descriptor/MeSH terms. A full article or report was retrieved for all that were deemed to be relevant. Articles identified from reference list searches were assessed for relevance based on their title. The individual substance of evidence was evaluated for all literature found, with strengths and weaknesses of the methodology and evidence being taken into consideration.

In order to gain a comprehensive understanding of the client-centred care concept, a broader literature search was included in the first phase of analysis. Upon completion of the first phase, the literature was restricted to focus more specifically on the home and community care sector.

2.1 Scope

This review focuses on home and community care clients, with consideration of the important transitions to and from other healthcare delivery sites and lessons learned from other clinical areas which could be replicated in the home and community sector. Although the focus was specifically on the Canadian experience, international literature was included within the review, where appropriate, to illustrate concepts that may be missing in, or could complement, the Canadian experience. This is particularly the case as it relates to client-centred care concepts, implementation, evaluation tools and specific experiences in the home and community sector.

Articles were included in the review based on their alignment with the operational definition of client-centred care endorsed by the project's National Advisory Committee, which is outlined in section 2.2.

Concepts relating to client-centred care such as partnerships, shared decision making, culture, language, education and power have been included within the Literature Review to the extent that they were discussed in the literature retrieved using the search terms indicated above.

Although closely related to the home and community sector, primary care, long-term care (nursing homes) and hospital care are outside the scope of this review. Principles and processes which influence care in the home and community care sector as it relates to these environments (e.g., transitions between care points) were considered within scope.



2.2 Definitions of terms to inform the scope of this review

To define the scope of the literature review, the following definitions were used:

Client-Centred Care

Client-centred care is "...an approach to the planning, delivery and evaluation of home and community care that is grounded in mutually beneficial relationships and partnerships among people using the healthcare system, their family and healthcare providers."

(adapted from the Institute of Patient and Family Centred Care, 2010).

Client

The term client, which is used throughout, is "inclusive of persons, families/significant others, groups, communities, and populations" (adapted from the Registered Nurses Association of Ontario [RNAO], 2002, p. 12).

Family

Family is defined as "two or more people, whether living together or apart, related by blood, marriage, adoption or commitment to care for one another" (Family Service Toronto, 2008).

Health

Health is defined as "a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity.

Within the context of health promotion, health has been considered less as an abstract state and more as a means to an end which can be expressed in functional terms as a resource which permits people to lead an individually, socially and economically productive life.

Health is a resource for everyday life, not the object of living. It is a positive concept emphasizing social and personal resources as well as physical capabilities" (World Health Organization, 1998, pg. 1).

Home and Community Care

Home and community care refers to "an array of services provided in the home or other closely related settings (such as adult day centres, community health centres) that enable individuals to live in their home environment and to function at their optimal level" (adapted from Health Canada, 2004a).



3. THE CANADIAN CONTEXT

Across Canada, the role of the home and community care sector in the provision of healthcare services is increasing and expected to continue to grow, with care increasingly shifting from the acute care environment to the community (Canadian Home Care Association [CHCA], 2008; Gantert et al., 2008; Romanow, 2002). There are some fundamental differences between providing care in the community versus within an institutional environment, which directly impact the way healthcare providers practice (Levin and Herbert, 2001; Magnusson, Severinsson & Lützén, 2003; Maitra & Erway, 2006; McCormack, 2004; McGarry, 2009).

At the same time, the way that clients receive healthcare is also changing. There is significant support for a movement in which clients play a more active role in their healthcare experience (Ball, 2010; Glover, 2005). This movement is supported by broader societal changes, including a focus on self-help/management, increased consumer rights movements and increased access to medical information (Ball, 2010; Cahill, 1998). There are strong and developing client and healthcare consumer organizations within Canada, which are advocating for systemic change and a new approach to healthcare that is focused on the needs of the individual (Ball, 2010; Glover, 2005).

This section explores the environment in which these changes are taking place, both in terms of the Canadian healthcare system as a whole, and particularly within the home and community setting. A summary of key examples of client-centred healthcare policy initiatives within Canada is provided. As healthcare policy sets the direction which guides actions, plans and outcomes, these examples help to illustrate the context in which these changes occur. This overview is followed by a summary of the structure of home and community care within Canada, and a subsequent exploration of how this sector provides a unique environment for the enactment of client-centred care.

3.1 Client-centred care in Canadian healthcare policy

Within this healthcare policy landscape, there is an increasing identification of the need to make healthcare systems more 'client-centred.' This language is used not only by politicians and healthcare providers, but is slowly translating into shifts at the policy and legislative levels.

In order to review developments in healthcare policy as it relates to client-centred care, a summary of key initiatives, which have been identified in the literature, has been compiled. This is not an exhaustive review, but rather a high level overview of activity to establish an appropriate understanding of the legislative and policy context.

As previously mentioned, significant challenges arise from the lack of consistency in the language and definitions of terms used to describe client-centred care, including those found in Canadian policy documents. The majority of documents refer to patient-centred care and to putting the client at the centre of the care experience.



Many provinces within Canada have taken steps to embrace a more client-centred care system, from policies and legislation that encourage a more client focused approach or reviews that seek to identify how citizens would like their healthcare system to work for them. A short summary of examples of these initiatives is included below.

3.2 Provincial and Territorial policy

Alberta Health Act - Alberta

During 2010, the Government of Alberta undertook an extensive consultation process that engaged Albertans regarding their views about the future of healthcare in Alberta and their views about the Alberta Health Act. In October 2010, the government announced acceptance of all the recommendations contained in the Alberta Health Act consultation report. These recommendations included: establishing principles in the Act that clearly put people first; mandating a Health Charter that acknowledges that health and healthcare are a partnership between individuals, families, communities, healthcare providers and the government; the establishment of a Health Advocate; and developing new approaches to public engagement on health legislation, regulation and policy matters (Government of Alberta, 2010).

Excellent Care for All Act - Ontario

In June 2010, the Ontario government formally accepted *The Excellent Care for All Act (ECFAA)*. The *Act* aims to "put patients first" by ensuring responsive, accountable and high quality healthcare service provision, which is focused on a positive patient experience.

The legislation sets out requirements for healthcare organizations that will be implemented first in the hospital sector and then expanded to include all healthcare organizations in the province. The legislation requires that healthcare organizations (*Excellent Care for All Act*, 2010):

- Establish quality committees that report on quality-related issues;
- Develop annual quality improvement plans which are available to the public;
- Link executive compensation to the achievement of targets set out in the quality improvement plan;
- Conduct patient satisfaction surveys;
- Conduct staff surveys;
- Develop a declaration of values following public consultation;
- Establish a patient relations process to address and improve the patient experience.



Local Health Integrated Networks - Ontario

In an effort to address disparate and uncoordinated healthcare services within Ontario, the Ministry of Health and Long-Term Care divided the province into 14 Local Health Integration Networks (LHINs) in 2006. Each LHIN was tasked with the planning, coordination and funding of local healthcare services including: hospitals, mental health and addiction services, community care access centres (CCACs), community support and service agencies, community health centres and long-term care homes. The rationale supporting this policy change was that it encouraged greater local engagement of community members (an important component of a client-centred system) in healthcare and, therefore, would work to develop a more integrated system by addressing relevant barriers and delivering more appropriate care (Local Health Integration Networks, 2010).

Of particular relevance to the home and community sector is the LHINs' administration of over \$700 million of funding through the Aging at Home Strategy, announced on August 28, 2007. This strategy has aimed to expand the community living options for seniors, enabling them to live healthy, independent lives in the community through the use of a broader range of home care and community support services (Ontario Ministry of Health and Long Term Care, 2010).

Patient First Review - Saskatchewan

In November 2008, the Health Minister of Saskatchewan announced the 'Patient First Review' (Dagnone, 2010). The review was called to address some of the healthcare challenges facing the province such as an aging population, increased chronic disease and competition for healthcare workers, access and quality challenges and rising healthcare expenditures. The review encompassed two distinct but related inquiries:

- Is the healthcare system meeting the needs of patients?
- Is the healthcare system achieving good value in care delivery and system administration?

An extensive public engagement strategy led to significant public involvement in the review, which resulted in 16 key recommendations for the healthcare system. Importantly, it emphasized the need for the healthcare system to be client-centred and defined this as care which is (Dagnone, 2010):

- Equitable;
- Coordinated;
- Timely and convenient;
- Informative;
- Comprehensive;
- Respectful; and
- Supported by functional e-health.



Primary Health Care Charter: A Collaborative Approach - British Columbia

In 2007, the British Columbia (B.C.) Ministry of Health released the Primary Health Care Charter which identified the direction, targets and outcomes for the primary healthcare system in B.C. The Charter outlines its commitment to a variety of client-centred changes including the following identified from the principles on which the document was based (British Columbia Ministry of Health, 2007):

- The improvement of patient health outcomes will drive action;
- Patients and families to assume the role of partners in their care;
- Identification and addressing of inequities and needs;
- Reorientation of health services to align with the patient's journey through a patient-centred, integrated health system;
- Accessible, appropriate, efficient, effective, safe quality care provided to patients at the right time in the right setting by the right provider;
- Patients and clinicians receive key information to make informed decisions at the point of care.

<u>Transforming New Brunswick's Health-care System: The Provincial Health Plan - New Brunswick</u>

New Brunswick's Provincial Health Plan was the result of consultation with the community and seeks to incorporate the priorities of stakeholders into the key goals identified through the plan. It recognizes the necessity of supporting a major shift towards a client-centred healthcare system to meet the needs and preferences of individuals and communities. The plan acknowledges that, "for people to become partners in their own care, they must have a sense that the system is willing to be more flexible" (Province of New Brunswick, 2008, pg. 9).

To realize this goal, the plan identifies the need to improve: access, technology, language barriers, integration (including with the home and community sector) and culturally sensitive care. It also acknowledges the importance of public engagement in the transformation of care to develop and foster partnerships with the public at both the process and systems levels (Province of New Brunswick, 2008). Importantly, the plan acknowledges the Extra-Mural program (home care services) as delivering client-centred care due to its nature and mandate (Province of New Brunswick, 2008).

3.3 Professional healthcare policy

There is widespread support for client-centred care within the healthcare professional policy literature. The Canadian Medical Association has recently released the document 'Health Care Transformations in Canada' in which the organization declares its support for a patient-centred system, defined as follows:



"Patient-centred care is seamless access to the continuum of care in a timely manner, based on need and not the ability to pay, that takes into consideration the individual needs and preferences of the patient and his/her family, and treats the patient with respect and dignity" (Canadian Medical Association, 2010, p. 6).

The document recommends the development of a Charter for Patient-Centred Care which would provide the foundation on which a culture of patient-centred care could be based. The Charter addresses the following key concepts (Canadian Medical Association, 2010):

- Dignity and respect;
- Access to care (timeliness, continuity, comprehensiveness);
- Safety and appropriateness;
- Privacy and security of information;
- Decision-making;
- Insurability and planning of health services;
- Concerns and complaints.

Other key professional groups, including nurses and occupational therapists, have indicated strong support for client-centred care. The RNAO published a Best Practice Guideline for client-centred care in 2002, which was subsequently revised in 2006. The guideline provides practical examples to facilitate client-centred care and outcomes, and focuses on the empowerment of clients, including their control and respect, and their experience of care (RNAO, 2002).

As a profession, Occupational Therapy has long supported the practice of client-centred care, working to define, implement, support and evaluate its practice within the Canadian system. The Canadian Association of Occupational Therapists (CAOT), in collaboration with Health Canada, released the first set of national guidelines based upon a client-centred approach in 1983 (Dow, Haralambous, Bremner & Fearn, 2006). These guidelines have subsequently been updated and revised and are referenced throughout the literature. CAOT's commitment to client based practice is further evidenced through the integration of client-centred care principles into the policy documents of the organization.



3.4 Home and community care in Canada

Home and community services are essential, available and growing in Canada for a myriad of reasons. An aging population, preferences of Canadians to remain in their home and receive care rather than be institutionalized, advances in medical technology, drugs and treatments that facilitate the delivery of care in the home and the mitigation of the high costs associated with acute care service delivery have contributed to the growth of this sector (CIHI, 2007; CHCA, 2008; MacAdam, 2004). Healthcare services provided in the community may be for short, acute periods of illness (e.g., following surgical intervention), however, the majority of clients receiving services in their home require longer term, supportive care (CHCA, 2008). These services can be provided in a wide range of settings including: individuals' homes, nursing homes, retirement homes, clinics, schools, group homes, hospices, reserves, and on the street for homeless populations (CHCA, 2008).

3.4.1 Legislation and Governance

Despite comprising an important role in the Canadian healthcare system, home and community services are not considered an 'insured health service' and, therefore, do not fall under *The Canada Health Act. The Act,* which guarantees all Canadians access to universal healthcare, does cover a limited number of home care services under 'extended healthcare services;' however, many services within the home and community care and social sector services are excluded (Canadian Home Care Human Resources Study, 2003; Health Canada, 2002; MacAdam, 2004). These non-insured home and community care services have been primarily funded by the Provincial/Territorial, municipal and local governments, with some funding allocated from transfers from the Federal Government (Health Canada, 2004b; CIHI, 2007). Despite an absence of a national legislative framework for home care, there are a handful of nationally-administered programs including: The Veterans Independence Program, the health services for the Canadian Forces and Royal Canadian Mounted Police (RCMP) and the First Nations and Inuit Home and Community Care Program (CHCA, 2008; MacAdam, 2004).

The Provinces and Territories are responsible for the scope, standards, governance and legislation of their provincial home and community care programs (CHCA, 2008). Consequently, 13 independent, but similar, healthcare systems designed to provide home and community care to their citizens have developed (CHCA, 2008; MacAdam, 2004; Romanow, 2002). As these separately administered provincial systems have grown, inconsistencies within and across jurisdictions related to the access, scope, delivery, and settings of home care services have emerged (Canadian Home Care Human Resources Study, 2003; CHCA, 2008; Canadian Medical Association, 2010).



3.4.2 Services

Formal home care services are an essential component of care in the community and play a role as a key link in the Canadian healthcare system, integrating care, improving the health and wellness of citizens and providing high quality care (CHCA, 2008). A variety of models exist for the delivery of home and community services including those which are a combination of public and private sector providers (CHCA, 2008; MacAdam, 2004). Although the systems and methods of service delivery differ across provinces, similarities do exist in that providers deliver a variety of healthcare services based on an assessment of need. In addition, the services are designed to complement individuals' self-care and the care received from friends, relatives, neighbours and the broader community (CHCA, 2008).

The nature of services delivered in the home and community environment ranges from assisting clients with daily personal tasks (e.g., dressing and toileting) and light housekeeping, rehabilitation, and administration of chemotherapy in the home through to palliative care (Health Canada, 2004a; MacAdam, 2004). A report by the Pan-Canadian Planning Committee on Unregulated Health Workers titled 'Valuing Health-Care Team Members: Working with Unregulated Health Workers' (2008) identified that the nature of services delivered in the community has become increasingly complex.

3.4.3 Workforce

Services within the home and community sector are provided by a diverse workforce incorporating the expertise and skills of a broad range of professionals and para-professionals including physicians, nurses, social workers, occupational therapists, dieticians, physiotherapists, speech therapists, nurse practitioners, recreational therapists, pharmacists, community health workers and unregulated health workers (Berkman, Gardner, Zodikoff & Harootyan, 2006; CIHI, 2007, CHCA, 2008). Unregulated health workers are known in the community by a range of titles including: homemakers, home support workers, home health aide, home attendant, personal support worker, healthcare aide, respite aide, palliative care worker, community health worker, nursing assistant, personal care worker, patient care assistant, and home health attendant, amongst others (Pan-Canadian Planning Committee on Unregulated Health Workers, 2008). These unregulated workers play an increasingly significant role in the community, as they comprise 60-70% of our healthcare human resources. Their role is to facilitate, through the provision of care services, the ability of individuals to remain in the community for as long as possible (Brookman, 2007).

The role of unregulated health workers continues to grow in the home and community sector for a number of reasons including: increased demand for service in the sector and a shortage of regulated health personnel to manage the workload (Pan-Canadian Planning Committee on Unregulated Health Workers, 2008). In addition to these paid healthcare providers, there are countless caregivers working in the home and community providing care for significant others, family, friends and neighbours, without remuneration. This workforce provides essential services within the community and helps to ensure that the healthcare system can continue to function despite the increasing demand for service (MacAdam, 2004).



3.5 Uniqueness of client-centred care in the home and community sector

The role of home and community care in the delivery of client-centred care is of great interest, particularly as the importance of context and environment of care delivery is understood in greater depth through research (Maitra & Erway, 2006; McGarry, 2009; Morgan & Moffat, 2008; Roush & Cox, 2000; Spiers, 2002; Wottrich, von Koch & Tham, 2007). The significance and complexity of the home environment has been explored in the literature (Holyoke, 2010; Ladd, Pasquerella & Smith, 2000; Reid, Angus, McKeever & Miller, 2003; Roush & Cox, 2000). There are numerous examples of how the healthcare system strived to deliver care, once only available in an institutional environment, to clients in the home and community, thereby making care more convenient, causing less disruption to the personal and professional schedules of clients and providing care in a less costly manner (in terms of finances and time) (Cousins et al., 2008; Livermore, 2003; Stevens et al., 2006).

The differences between care in the home or community setting and acute care have been explored in an abundance of literature (Ladd et al., 2000; Levin and Herbert, 2001; Magnusson et al., 2003; McGarry, 2009; Gibson, Timlin, Curran & Wattis, 2007; von Koch, Wottrich & Holmqvist, 1998). Results from a qualitative study conducted by von Koch, Wottrich & Holmqvist (1998) in Sweden concluded that context was an important element in the rehabilitation of clients post stroke. The small qualitative study found that clients receiving care in the home and community setting demonstrated greater initiative and confidence over their treatment, thus promoting their participation in care and goal setting, when compared to clients who received care in the hospital environment, which was viewed as a foreign setting (von Koch et al., 1998).

The importance of the context of home care was further supported in a subsequent study, which examined the meaning of rehabilitation in the home environment. The authors found that the contextual factors in the home gave a group of therapists insight into the client's life, which enabled them to plan care tailored to the individual and assist clients to find continuity in their lives (Wottrich et al., 2007). These findings were echoed in an evaluation conducted by Gibson et al. (2007), which compared a clinic and a community service model of dementia care services. Interviews with ten clients with mild to moderate dementia who were asked about their experiences revealed that, while both models of care delivery were acceptable to clients, those receiving care in their home reported "a greater perception of control and empowerment over their own treatment" (pg. 274).

The home and community setting provides a unique opportunity for client-centred care, as care is rooted in the client's 'real life' environment, allows the healthcare provider greater insight into the lives of their clients and therefore, a more in-depth understanding of the client (Brown, McWilliam & Ward-Griffin, 2006).



In this environment, it has been proposed that clients may have equal or greater control/power in the relationship with a healthcare provider (Carr, 2001, cited in McGarry, 2009). Conversely, it has been reported that the client may view care in this home environment as an invasion of privacy or encroachment on their space (Angus, Kontos, Dyck, McKeever & Poland, 2005; Magnusson & Lützén, 1999).

Despite the advantages for clients receiving care in the home and community, the complexity of this environment for the healthcare provider has also been highlighted. von Koch et al. (1998) indicated that rehabilitation providers working in the community adopted a multitude of roles in their homebased interaction with their client, including assuming roles of visitor, friend and student while providing healthcare to the client, all of which were quite distinct from the primary roles that they enacted within the hospital environment, of both teacher and expert. This finding was supported by qualitative studies conducted in Sweden by Magnusson et al. (1999; 2003), which explored and described how the experiences of systemic and policy changes to the environment of care (shift to the community) influence interactions with patients who have long-term mental health problems. Nurses cited ethical dilemmas in their provision of care in the home, specifically as it related to issues of privacy, autonomy, trust and challenges while they negotiated their role as one of nurse versus intruder (Magnusson et al., 1999). However, the community environment also enabled the development of understanding and partnerships with clients following transition to the community. Relationships developed based on a clearer understanding of the client and their strengths and abilities, communication patterns changed, and negotiation and trust were used to enhance client's self-determination and achievement of goals (Magnusson et al., 2003).

Although the home and community setting provides unique opportunities for the delivery of client-centred care (Borg, Karlesson, Tondora & Davidson, 2009; Brown et al., 2006; Restall & Ripat, 2008), the practice setting alone is not sufficient to make practice client-centred. Further interventions and strategies are required. In the first phase of unpublished work by Holyoke (2010), the author examined the experience of clients in terms of their expectations of home care and, particularly, of personal support services (performed by unregulated health workers) in Ontario, Canada. The findings demonstrated that while clients are largely satisfied with home care services, they expect the services they receive to be better than if they were in a long-term care home, and to be care that 'recognizes and honours them as people with lives, histories and futures, not simply treating them as people with bathing or mealtime needs" (Holyoke, 2010, pg. 27). In essence, clients expect their care to be client-centred.



4. WHAT IS CLIENT-CENTRED CARE AND HOW IS IT DEFINED?

4.1 Background

There is a significant body of work which aims to describe what is meant by the term 'client-centred care.' Despite the popularity of the concept and its increased prominence, it is not novel. These approaches date as far back as the ancient Greeks, who were interested in each individual patient (de Haes, 2006; Stewart et al., 2000). Modern literature concerning the phenomenon of client-centredness has been documented since the mid-1950s, with early work attributable to scholars including Michael Balint and Carl R. Rogers, who are credited with setting the foundations of this practice. This was followed by the development of the bio-psychosocial model of George L. Engel, which further facilitated growth and exploration in this area (Adams & Drake, 2006; Bauman, Fardy, & Harris, 2003; Beach & Inui, 2006; de Haes, 2006; Dow et al, 2006; Wressle & Samuelsson, 2004).

From the 1980s onwards, client-centred care has grown in prominence in both the academic and policy literature (Adams & Drake, 2006; de Haes, 2006). At the same time, there has been a shift in healthcare practices, from models that traditionally have supported a task-based, hierarchical, or medical model, of healthcare, where professionals 'do for' and/or 'do to' clients (a clinician-centred approach) towards a model which seeks to develop a broader, more holistic understanding of clients, empowering them to be a participant or partner in their healthcare (Adams & Drake, 2006; Brown, et al., 2006; de Haes, 2006).

Within this context, there have been key developments, which have impacted upon the research and practice of client-centred care. In 1993, a seminal publication by Gerteis, Edgman-Levitan, Daley, Delbanco and Hobbins titled 'Through the Patients Eyes: Understanding and Promoting Patient Centred Care' helped to change and refine the concept of patient-centredness. This book is still highly referenced within the literature produced today. Subsequently, a landmark American report was published in 2001 by the Institute of Medicine (IOM) titled 'Crossing the Quality Chasm: A New Health System for the 21st Century.' By including patient-centred care as one of the six essential aims of quality medicine in the American healthcare system, this report helped to cement the importance and relevance of client-centred care in the delivery of high quality client care and ensure that it becomes a focus of service delivery (Silow-Carroll et al., 2006).

4.2 Conceptualizations of client-centred care across healthcare disciplines

As discussion about the importance of client-centred care has evolved, so too has the terminology used to describe it. Client-centred care is just one among many terms used in the literature to address the phenomenon of practice which puts the client 'at the centre of care.' Family-centred, personcentred, patient-centred, people-centred, person-focused, client-focused, and client-driven are all terms, which have, at times, been used interchangeably. However, despite perceived similarities, these concepts may actually have different meanings (Cott, 2004; Edvardsson et al., 2008).



The multiplicity of terms used to address client-centred care has resulted in a 'poorly conceptualized' term with numerous definitions utilized to describe it (de Haes, 2006; Hobbs, 2009; Robinson et al., 2008; Mead & Bower, 2000a). This inconsistency in the literature and practice has had consequential impacts on the implementation and interpretation of client-centred care (Hobbs, 2009; Robinson et al., 2008).

Additional complexity arises when one considers that the existing definitions and literature base supporting client-centred practice in healthcare is largely discipline-specific, with work in this area evident in nursing, allied healthcare (occupational therapy, physiotherapy, and speech and language therapy, dietetics), medicine, pharmacy and recreational therapy (Cott, Boyle, Fay, Sutton, Bowring & Lineker, 2001; Cott, 2004; Dow et al., 2006; Hobbs, 2009; MacLellan & Berenbaum, 2007). As each discipline has interpreted and applied client-centred care within its scope of practice, there are significant differences in how each conceptualizes and operationalizes the term (Cott et al., 2001; Cott, Teare, McGilton & Lineker, 2006).

The medical literature refers primarily to the terminology of "patient-centred care," focusing on the development of relationships with clients (through specific practices within the care process, such as communication and care planning) and viewing the healthcare journey from the client's perspective (Bauman et al., 2003; Cott et al., 2001; Gerteis et coll., 1993; Hobbs, 2009; MacLellan & Berenbaum, 2007; Mead and Bower, 2000a; Stewart et al., 2000). The medical literature on patient-centred care is extensive in the area of primary care practice; however, Mead and Bower (2000a) report that it is increasingly found in specialties like paediatrics and oncology.

Citing multiple definitions of client-centredness, the nursing literature has a long history of client-centred care (Hobbs, 2009). MacLellan and Berenbaum (2007) identify that nursing conceptualizations of client-centred care often incorporate an operational approach, where the clients are at the centre of care with services around them. A philosophical approach has also been proposed, which stresses the importance of services that meet the individual needs, values, preferences and desires of clients, while facilitating the development of the nurse-patient relationship and partnerships in care (Millers & Koop, 1984, cited in Cott et al., 2006; Mitchell, Clossen, Coulis, Flint & Gray, 2000; MacLellan & Berenbaum, 2007).

Client-centred practice has been explored within the occupational therapy literature for over 20 years and, thus, reflects a lengthy history of the subject within Canadian practice, where client-centred practice is seen as an integral part of care in all clinical settings (Dow et al., 2006).



There is relatively little literature which examines client-centred care from an integrated, multidisciplinary approach (Cott, 2004; Hobbs, 2009). As healthcare providers work collaboratively across a variety of clinical areas throughout the healthcare continuum, the multiple approaches to client-centred care raise particular challenges to accurate interpretation of the literature and application of the concepts in multi-discipline practice environments, such as rehabilitation services and home and community care sectors (Cott, 2004; Cott, Wiles & Devitt, 2007). There is general agreement in the literature that a need exists to consolidate definitions and create an agreed-upon meaning for client-centred care (Gillespie, Florin & Gillam, 2004; Mead & Bower, 2000a; Robinson et al., 2008).

4.3 Client-centred care terminology

As stated previously, there are several terms used in the literature to describe client-centred care or closely related concepts. This makes it challenging to discuss client-centred care in isolation as, despite their differences, the terms all share fundamental synergies which place a "focus on the person rather than the disease" (Edvardsson & Innes, 2010, pg. 836). This section will explore the similarities and distinctions between client-centred care and these related terms.

4.3.1 Patient-centred care

Patient-centred care and client-centred care appear to be used almost interchangeably in the literature, with both terms focusing on the provision of care that focuses on the needs of the individual. The term patient is used most commonly in the hospital (acute) care setting (Hobbs, 2009) and in the medical literature (Bauman et al., 2003), often used in reference to communication and seeing care "through the patient's eyes" (Gerteis et al., 1993). In contrast, the term "client-centred" is primarily used in the home and community sector, acknowledging that the client is at the centre of care and service (Edvardsson & Innes, 2010).

The term "client" is considered by some to be preferable to "patient" due to the perception that "patient" is illness-centred, placing the focus on a person's illness, rather than on the person themselves, who is a client of the service (Edvardsson & Innes, 2010).

4.3.2 Person-centred care

Person-centred care is a term most commonly used in the gerontological and dementia literature (Kitwood, 1997). This body of literature is highly relevant within the home and community sector due to the demographics of clients receiving care in the community and the high incidence of dementia services provided in this context (Health Canada, 2004a).



Much of the person-centred literature is underpinned by the social-psychological theory of personhood in dementia developed by Kitwood and colleagues at the Bradford Dementia Centre (Kitwood, 1997). The concept has subsequently been applied more broadly to refer to care for older adults. Central to person-centred care is the concept of personhood, which is described as: "...a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, pg. 8). Each person is understood to have a unique story, experience and perspective, which contribute to them as an individual.

Person-centred care essentially seeks to preserve the 'personhood' of the individual (Edvardsson et al., 2008; Epp, 2003). A review of person-centred care in gerontological nursing by McCormack (2004) outlined four concepts at the heart of person-centred care:

- **Being in relation** the importance of relationships between nurse and client, 'knowing' the person and their social context, including the person, their community and the formal/informal caregivers.
- **Being in a social world** incorporating different methodologies, such as biographical narratives and life plans into a thorough assessment of a client and subsequent development of a care plan which ensures their social world remains central.
- **Being in place** understanding and appreciating how the environment influences the provision of care.
- **Being with self** the importance of having an understanding of a person's values, which can form the basis of a partnership between nurse and client.

The concepts surrounding person-centredness are generally reflective of a client or patient-centred approach to care, incorporating similar key principles and a shared understanding of the importance of developing an understanding of the individual, their environment, values, relationships and social world. In terms of terminology, Edvardsson et al. (2008) suggest that 'person' is preferable to the term 'patient,' as the former respects the 'holistic humanness' of the person, whereas 'patient' implies that there are 'imperfections or undesired differences' to a person (Edvardsson et al., 2008, pg. 363). As indicated earlier, the term person-centred care has emerged as the most reflective of this holistic approach to healthcare, although the term 'client' was used as the focus of this specific review of the literature.

The concept of person-centred care has been challenged in the gerontological literature as being too focused on the person and failing to "...fully capture the interdependencies and reciprocities that underpin caring relationships" (Nolan et al., 2002, pg. 203). An argument is made for the need to go beyond an approach which is centred on the person, to one which focuses more specifically on the relationships that the person holds. This approach is known as relationship-centred care.



4.3.3 Relationship-centred care

Relationship-centred care emerged from the American Pew-Fetzer Task Force on Advancing Psychosocial Education (1994), which highlighted the centrality of relationships in healthcare (Nolan, Davies & Brown, 2006; Tresolini & the Pew Fetzer Task Force, 1994; Wylie & Wagenfeld-Heintz, 2004). It is a concept which appears not only in the gerontological literature, but has also emerged within the medical context. It is defined by Beach & Inui (2006) as "...care in which all participants appreciate the importance of their relationships with one another" (pg. S3). The authors outlined four principles upon which relationship-centred care is built (pg. S4):

- Relationships in healthcare ought to include the personhood of the participants;
- Affect and emotion are important components of these relationships;
- All healthcare relationships occur in the context of reciprocal influence;
- The formation and maintenance of genuine relationships in healthcare is morally valuable.

The relational process empowers patients as partners. The focus is on the relationship between the client and clinician, and the relationships of clinicians with themselves, their team, family members and the community are also emphasized (Beach & Inui, 2006; McWilliam, 2009).

4.3.4 Family-centred care

Family-centred care is similar to client-centred care in that it appears in the literature in a number of different contexts and there is no agreed upon definition (Shields, Pratt and Hunter, 2006). Family-centred care indicates "an approach to care in which the family is viewed as the unit of care, rather than just the identified patient. This approach is consistent with a client centred approach where each individual's meaning of 'family' is respected and families are viewed as an integral whole" (RNAO, 2002, pg. 3).

The majority of the family-centred care literature specifically addresses the paediatric setting. However, family-centred care can be provided in the community, institution or a combination of the two (Litchfield & MacDougall, 2002).

4.3.5 Demand-oriented care

Demand-oriented care is referenced in the client-centred care literature from European countries, particularly the Netherlands. It represents an interpretation of client-centred care that has been defined as "a collaborative effort of both the client and the professional, resulting in care that meets the client wishes and expectations and at the same time meets the professional standards" (Raad voor de Volksgezondheid [RVZ], 1998, cited in Schoot, Proot, Ter Meulen & de Witte, 2005a, pg. 371). The concept is highly reflective of client-centred care; however, it appears to place more onus on the client to identify their needs. The shift towards consumerism in healthcare makes the research regarding demand-oriented care highly relevant within the Canadian home and community care context.



4.3.6 Client-directed care

Client-directed care is also a term used and studied within the home and community sector in Canada. It is defined by the RNAO (2006) as "an approach to care delivery where clients are considered the brokers of care, and receive what they ask for" (pg. 2). This definition involves the client taking an active role, controlling care delivery not just at the point of care, but in the broader healthcare system.

4.3.7 Consumer-directed care (Personalization)

Consumer-directed care is closely related to the term personalization, which appears in the literature from the United Kingdom (UK), regarding the orientation of services around clients and their preferences. It has been defined by the UK Department of Health (2008) as referring to the process whereby "people are able to live their own lives as they wish, confident that services are of high quality, are safe and promote their own individual requirements for independence, well-being and dignity" (cited in Slasberg, 2010, pg. 15). This is closely related to the concept of client-centred care as it empowers clients to have a choice in the services required and how these are executed and is explored in greater detail in Section 5 of the review.

4.3.8 Patient-focused care

Patient-focused care appears often in the nursing literature and is largely related to the reorientation of hospital-based services to meet the needs of clients (Cott, 2004; Hobbs, 2009). It has been described as a "philosophy of care that defines the patient's needs as the primary and paramount factor in shaping care delivery practices and processes and all of the supporting services" (Booz-Allen & Hamilton, 1993, cited in Jenner, 1998, pg. 1087) and incorporates strategies such as extended roles (role redesign) within a multidisciplinary team.

4.4 Client definitions of client-centred care

There is significant evidence to suggest that considerable discrepancies exist between the perspectives of clients and care providers in relation to healthcare service provision, client preferences and the goals and outcomes which are important to clients (Cott, et al., 2007; Cott, 2004; Eloranta, Arve, Isoaho, Welch, Vitanen & Routasalo, 2010; MacLellan & Berenbaum, 2007; Themessl-Huber, Hubbard, & Munro, 2007). A study by Maitra and Erway (2006) highlighted that this may also be the case in relation to perspectives regarding client-centred care and their participation in related activities (e.g., goal setting). There has been relatively little work undertaken to understand client-centred care from the perspective of the client (Corring & Cook, 1999; Cott, 2004); however, this is an area gaining increased attention from researchers.

One of the key sources of information regarding the client's perspective of client-centred care is The Picker Institute. Widely recognized as a leader in the definition, promotion and evaluation of client-centred care, this organization has both American and European representation.



Based largely on the pioneering work conducted by Gerteis et al. (1993), the organization has, over the course of two decades, worked to identify Dimensions of Patient-Centred Care and has actively engaged clients in their development. These dimensions are the basis for many institutional (largely acute care focused) definitions of patient-centred care and include (Gerteis et al., 1993, pg. 5-10):

- 1. Respect for patients' values, preferences, and expressed needs;
- 2. Coordination and integration of care;
- 3. Information, communication and education;
- 4. Physical comfort;
- 5. Emotional support and alleviation of fear and anxiety;
- 6. Involvement of family and friends;
- 7. Transition and continuity.

In the Canadian context, Cott (2004) conducted a qualitative study in order to understand the important components of client-centred rehabilitation from the perspective of the client. The study engaged 33 clients who had adult-onset, chronic, disabling conditions (e.g., arthritis, total joint replacement, acquired brain injury, chronic respiratory conditions, spinal cord injury and stroke) and had completed at least one course of rehabilitation, in the publicly-funded Ontario healthcare system. A total of six focus groups were held with the study participants who provided their insights. An iterative inductive approach was used for the data analysis which revealed the important components of client-centred rehabilitation (as defined by clients), including (pg. 1419):

- The need to develop individualized programs to meet client needs;
- The need for clients to participate in decision-making and goal setting;
- The identification of outcomes which have meaning for the client;
- The sharing of information and education that is appropriate, timely and according to the clients' wishes;
- The provision of emotional support;
- The involvement of family/peers;
- The coordination and continuity of care across the sectors (transitions).

These findings demonstrate that the client-identified components extended well beyond the clinically-based activities such as participation in decision making and goal setting, despite the fact that they are often the focus of professional discourse regarding client-centredness. Clients conceptualized client-centred care as a broader approach to the management of the rehabilitation experience. This included the development of partnerships between themselves and a healthcare provider, who could understand and respect their individual needs (pg. 1418). Of particular interest was the participants' concerns with their goals relating to role transitions from 'patients' within the rehabilitation setting to that of persons living in the community with a disability (Cott, 2004).



In another Canadian study in southwestern Ontario, Corring and Cook (1999) recruited 17 clients of the mental health system (community and acute) to participate in a series of focus groups aimed at exploring their perspectives of a client-centred system. Importantly, this study also embraced the client perspective in the research design by recruiting two clients to work as members of the project team. Participants identified both what was missing from the current system and what they would expect from a client-centred system. They described an existing healthcare system which reinforced stigma and lacked flexibility and accountability. They recounted interactions with healthcare providers that did not meet their needs or reflect a true understanding of them as a person. These negative experiences reinforced traditional power imbalances and led to feelings of fear, poor self-esteem, disempowerment and marginalization. Conversely, clients described a client-centred system as one which 'valued them as a human being', allowed them to contribute to 'fixing' the system and incorporated programs that empowered clients and addressed power imbalances through the practice of partnerships between clients/providers. The relationship with providers in a client-centred system would value their knowledge and facilitate the development of a true understanding of the client, over time. The authors acknowledged the importance of a continuation of research in this area to further the understanding of the client's perspective and thus, the practice of client-centred care, especially as the client perspective is key to this practice.

In the Netherlands, Schoot et al. (2005a) conducted a qualitative study which sought to examine client perspectives of client-centred care in the home and community setting. A sample of 45 clients and 8 client 'informants' (clients with chronic illness or their family members, who work with the Dutch Council of the Chronically III and contribute to the work based on their own personal experiences and those fellow members of their association) were recruited to participate in the study which included focus groups, client interviews and participatory observations between healthcare providers and clients in the home setting. When the researchers analyzed the observational data focused on the interactions between clients and nurses, different patterns of participation were identified. Participation in this context referred to the desired level of responsibility and initiative in decision making processes, management of care and the independence in care, which were exhibited by both the nurse and client (Schoot et al., 2005a). These patterns of care are outlined in Table 1.



Table 1 - Patterns of interaction

Toeing the line	The nurse directs care, with no recognition of the client's wishes; the client assumes a passive role and avoids confrontation.
Reluctance	The nurse is attentive but critical in his/her approach to client wishes or development of autonomy; client is reluctant to participate in nursing.
Fighting	The client struggles for self-governance; care is directed by the nurse, the client confronts the nurse when his/her wishes are not recognized.
Consent	The nurse directs care; client wants and works to enhance nurse directed care.
Dialogue	The nurse and client are equal, interdependent partners in care; client wishes are recognized, discussed and clarified.
Consuming	The nurse gives information and completes tasks as instructed and client assumes business instead of care.

^{*}Adapted from Schoot et al., 2005a, pg. 384.

The results of the study indicated that the participants perceived care as being client-centred when it was congruent with their desired level of participation (Schoot et al., 2005a). This congruence was demonstrated, and therefore client-centred care was realized, in the patterns where the clients were able to experience their desired level of participation, either through collaboration and/or partnership with the nurse, or through client demand. This was observed in the 'consent,' 'dialogue' and 'consuming' patterns. Where the interactions between the nurse and client were identified as fitting the pattern of 'toeing the line,' 'reluctance' or 'fighting,' there were discrepancies between what the client preferred and the care facilitated by the nurse; therefore, it was deemed as not client-centred.

In a subsequent study conducted by Schoot et al. (2005b), the researchers sought to explore the perspectives of people with chronic illness and their caregivers in terms of their client-centred interactions with home care staff. Study participants identified the values underpinning their 'demand' or preferences for healthcare service delivery. These included:

- Autonomy (having the possibility to be who you are and self-determination);
- Continuity of life (flexible care in order to continue to live);
- Uniqueness (understanding of the individual demands and wishes of each person);
- Comprehensiveness (the desire to be seen as an integral human being);
- Fairness (equal distribution of care, according to needs).



Three values were identified as underlying the relationship that the clients had with the healthcare provider:

- Equality (experience-based knowledge is just as valuable as professional knowledge);
- Partnership (accountable, committed and active partners in care);
- Interdependence (mutual respect, trust and acceptance).

Importantly, results from these studies illustrated that some clients did not want to participate in decision making and/or felt unable to do so (de Witte, Schoot & Proot, 2006). Such findings are important for the practice of client-centred care as they highlight the importance of individual preferences for interactions in care. There are no 'one size fits all' solutions for client-centred care, as the purpose of the practice is to work with the client to determine an understanding of the care that they desire and require.

4.5 Central themes of client-centred care

The definitions of client-centred care identified in this literature review can be grouped into two broad categories; process-oriented definitions and system-oriented definitions:

<u>Process-oriented</u>: those which refer to the adoption of the client's perspective and address the provision of care to the individual (at the point of care);

System-oriented: those which provide a global, systems perspective on what constitutes client-centredness, acknowledging the importance of involving the person not only at the point of care, but more broadly within the healthcare delivery system (Cott, 2004; Cronin, 2004; Pelzang, 2010).

Although these themes are not mutually exclusive, they will be used throughout the literature review (where appropriate) to provide structure to the document, framing both the discussion and analysis of client-centred issues and concepts.



5. APPROACHES TO THE IMPLEMENTATION OF CLIENT- CENTRED CARE

In order to provide a more complete understanding of client-centred care, an overview of models or approaches to client-centred care, which are appropriate for use in the home and community context, is included below (Dow et al., 2006). The section begins with an overview of a sample of theoretical models of client-centred care which can guide practice in the home and community sector. This is not intended to be an exhaustive list; rather, a selection of models that can inform clinical practice. Where available, evaluation data have been included to support the model discussed. Next, some practical examples of client-centred care models are included in order to demonstrate how this care can be enacted in practice. Finally, a sampling of other approaches to care that could be regarded as fundamentally client-centric are discussed.

5.1 Theoretical Models

Theory plays an important role in healthcare delivery as it seeks to describe relationships and interactions and provide structure to complex constructs. There are, however, few theoretical models specifically identified as client-centred care reported in the literature, which has been attributed to the lack of consensus regarding what constitutes client-centred care (Mead & Bower, 2000a). Of the theoretical models noted, many have been applied within the acute care context, with limited evidence to support their effectiveness in the home and community setting. This represents an opportunity for further exploration and development, with a need to also develop more evidence to support the use of existing theories in all healthcare settings, including the home and community (Brown et al., 2006).

5.1.1 Human Becoming Theory

Parse's Human Becoming Theory has been implemented in several nursing environments. "Grounded in the humanities and existential-phenomenological thought," the theory emphasizes the person at the centre of nursing care (Legault & Ferguson-Pare, 1999, pg. 30) and identifies that the goal of care is delivering 'quality of life,' as perceived by the person, family or community (Parse, 1992). The theory is based upon the nurse achieving 'true presence' with a person as they explore the meaning of their life situation, illuminating their perspective about what they are experiencing and making choices and plans for themselves, based on their internal priorities/values (Parse, 1992). The person's subjective experience of health guides the interaction between the nurse and the client and the nurse is responsible for "being-with" the person in a non-judgmental and attentive manner and being clear that the person, family or community's view is the most important and will guide the nursing process (Parse, 1998, cited in Bournes, 2002).



The Human Becoming School of Thought is seen as being distinct from other nursing theories and Bournes (2002) states that its application requires "a commitment to significant change in nurses' values, beliefs, and practices" (pg. 190) and that nurses guided by Human Becoming Theory "live a set of values and assumptions that require a commitment to honouring persons as unique and unitary" (pg. 191). Human Becoming client-centred care has been described as combining the "organizational commitment to support professional practices that address and meet concerns, needs, and expectations of persons receiving care with a theory that can provide the knowledge, the know-how, to practice in this way" (Mitchell, Bournes & Hollett, 2006, pg. 218).

Although a nursing model, Human Becoming Theory has also been implemented in the work of Therapeutic Recreationists as part of a Canadian action research project by Pedlar, Hornibrook, and Haasen (2001). Through the use of reflective practice, the process allowed the professionals who participated to explore this healthcare role in the context of client-focused care, challenging the manner in which care was provided and resulting in opportunities to examine and implement practice changes. For example, the assessment process was revised to be more engaging and encompassing of the client's preferences (Pedlar et al., 2001).

A large amount of research has been conducted examining the Human Becoming Theory, its practice and research. Although a thorough review of this evidence is beyond the scope of this report, articles by Bournes (2002), who completed a synthesis examining the nurse and client experiences when using the theory in practice, and by Doucet and Bournes (2007), who completed an extensive review of human becoming-guided research studies (n=93), may be referred to for further information.

5.1.2 The Tidal Model

The Tidal Model is a client-centred model of the provision of mental health nursing care (Barker, 2001). Although it was originally developed for an acute care setting, the application of the model is suitable for any environment where clients with mental health concerns seek care. Using water as the core metaphor to represent the fluidity of life, this theory focuses on the support needed by people at different times to help pull them back onto their 'life development course,' or rescue them from crisis (Barker, 2001, pg. 235).

The Tidal Model has three different, but related, dimensions of care (Fletcher & Stevenson, 2001, pg. 34):

- 1. World dimension focuses on the person's need to be understood;
- 2. Self dimension focuses on the person's need for physical and emotional security;
- 3. Others' dimension emphasizes the kinds of support the person might need from a wide range of people and agencies to be able to live an ordinary life.



The theory acknowledges the disempowerment of a mental health challenge, emphasizing the importance of not reducing a client to a 'patient' phenomenon (Barker & Buchanan-Barker, 2010). The model highlights the centrality of the person, with the role of the care provider being to help individuals explore and tell their own story, including their experience with illness and health, identification of their own issues/challenges and ways to address these (Barker, 2001; Barker & Buchanan-Barker, 2010).

The Tidal Model has been piloted in Canada, as well as internationally, including pilot programs in Australia, England, Ireland, Japan, New Zealand, Scotland and Wales (Fletcher & Stevenson, 2001). It has been implemented in a range of clinical settings from rural, community services to acute care wards and in forensics (Barker, 2001; Barker & Buchanan-Barker, 2010; Jacob, Holmes, & Buus, 2008) and, although focusing primarily on the role of nurses in mental health, it has also been applied in an interdisciplinary plan of care (Berger, 2006). Evidence from reported case studies on the implementation of the Tidal Model in acute care settings, which have measured outcomes including client and professional satisfaction, number of admissions, length of stay, violent incidents, episodes of self-harm and the use of restraints, revealed some positive effects for the model on the care provided (Fletcher & Stevenson, 2001; Barker & Buchanan-Barker, 2010).

5.1.3 Canadian Model of Occupational Performance (CMOP)

The Canadian Association of Occupational Therapists has developed the CMOP which illustrates occupational therapy's approach to client-centred practice in Canada (CAOT, 2002, p 33). This represents one of the few discipline-specific theoretical models which can be used as the basis for client-centred practice (Sumsion, 2006). The model, originally based upon the work of Reed and Sanderson (1980), has been developed and refined over several years (Sumsion, 2006). Client-centred practice in occupational therapy is conceptualized as promoting health through the enabling of occupation (CAOT, 2002). There is no standard, broadly accepted definition for occupation; however, the CAOT publication 'Enabling Occupation: An Occupational Therapy Perspective' defines it as "groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and culture. Occupation is everything people do to occupy themselves...." (CAOT, 2002, pg. 34).

The CMOP depicts (using a three dimensional image) the dynamic interdependence between the person (at the centre), occupation (the middle) and environment (outer). This acknowledges that if a change occurs within any aspect of the model, there are consequences for all other aspects. The model has broad applicability and can be used for a variety of populations in a myriad of settings (CAOT, 2002). The components of the person include the inter-related and inter-dependent affective (feeling), cognitive (thinking) and physical (doing) dimensions (Sumsion, 2006).



At the centre of all interactions between the person/environment and occupation is spirituality (CAOT, 2002), which plays an important role in occupational therapy. The components of occupation include: self-care (occupations for looking after the self), productivity (occupations that make a social or economic contribution or that provide one with economic sustenance) and leisure (occupations for enjoyment) (CAOT, 2002, pg. 37). The environmental components include: cultural (e.g., racial, ethnic, ceremonial practices based on ethos and value systems of groups); physical (e.g., natural and built environments); social (e.g., social priorities about all elements of the environment, patterns of relationships of people living in organized communities, social groupings based on common interests, values, attitudes and beliefs) and institutions (e.g., societal institutions and practices) (Sumsion, 2006).

5.1.4 Authentic Consciousness

McCormack (2003) developed a conceptual framework for person-centred care practice in older adult populations; the Authentic Consciousness framework highlights the role of partnerships between nurses and clients based on negotiation of care, incorporating the client's values and beliefs. It is derived from research that explored the meaning of autonomy for the elderly in hospital settings and identified a number of factors which restrict autonomy.

McCormack proposes that person-centred care is realized through an understanding of the individual's authentic values, which are achieved through 'authentic consciousness,' defined as a "consideration of the person's life as a whole in order to help sustain meaning in life" (McCormack 2003, pg. 204) through the understanding of a client's values and beliefs, which are conceptualized as deeper than the acknowledgment and respect of a client, their individuality and preferences. The role of the nurse is to develop a relationship with a person and facilitate the opportunities for decision making that are true to a person's life as a whole.

The Authentic Consciousness framework suggests that the relationship between a nurse and a client develops based on getting to know the client through consideration of the patient's authenticity, the completion of 'imperfect duties' and the consideration of contextual factors (McCormack, 2003). 'Imperfect duties' are described as wide, broad, limited and un-enforceable (e.g., compassion or benevolence) and are contrasted against 'perfect duties' which are defined as being strict and enforceable (Sullivan, 1990, cited in McCormack, 2003, pg. 204). The framework specifies five imperfect duties which act as guiding principles, interpreted within the context of a particular relationship/situation (McCormack, 2003, pg. 204):

Informed flexibility:

• The facilitation of decision making through information sharing and the integration of new information into established perspectives and care;

Mutuality:

The recognition of the others' values as being of equal importance in decision making;



Transparency:

• Making explicit the intentions and motivations for action and the boundaries within which care decisions are set;

Negotiation:

 Patient participation through a culture of care that values the views of the patient as a legitimate basis for decision making, while recognizing that being the final arbiter of decisions is of secondary importance;

Sympathetic presence:

• An engagement that recognizes the uniqueness and value of the individual by appropriately responding to cues that maximize coping resources through the recognition of important agendas in daily life.

The framework acknowledges the fluidity and dynamic nature of the nurse-client relationship, which exists in a continuum from engagement, partial disengagement to complete disengagement, depending upon the situation faced and the context. It also stresses the role of the clients' values, the nurses' values and expertise and the context of the care in the achievement of Authentic Consciousness. This context of care, and the role of the organization in the nurse-client relationship, plays an important role in the facilitation of decision making.

In summary, the Authentic Consciousness framework describes a person-centred approach to nursing whereby the nurse and client enter into a dynamic relationship, acknowledging the client's authenticity and facilitating an older person's maintenance of individual autonomy through negotiated partnerships and decision making.

5.1.5 The Senses Framework

The 'Senses Framework,' developed by Nolan et al. is largely based on the concept of relationship-centred care. Focusing on the dimensions of caring relationships, the Senses Framework reflects the experiences of both clients and staff in the context of a caring relationship (Nolan et al., 2004). The framework is based on a belief that in order for good care to be achieved for the client, all people who have been involved in providing care for the person (e.g., informal/formal caregivers, family, the client, etc.) need to experience the 'senses' listed below (Nolan, Davies & Brown, 2006, pg. 9):

A sense of security:

• To feel safe and receive or deliver competent and sensitive care;

A sense of continuity:

• Recognition of biography, using the past to make sense of the present and helping to plan the future; working within a consistent team using an agreed philosophy of care;



A sense of belonging:

• Having opportunities to form meaningful relationships and to feel part of the community of the home, whether as a resident or staff member;

A sense of purpose:

• To have opportunities to engage in purposeful activity, or to have a clear set of goals to aim for;

A sense of fulfillment:

To achieve meaningful or valued goals and to feel satisfied with one's efforts;

A sense of significance:

• To feel that you, and what you do, matter, and that you are valued as a person of worth.

The Senses Framework has continued to evolve since its inception, through inclusion in a number of large studies exploring care for older people in a variety of settings, including the community (Nolan, Davies & Brown, 2006). Developments have included the application of the framework to understand 'impoverished' and 'enriched' care environments and how these impact on education of care providers and the care provided to older people. Enriched environments in this context are those where all participants (the client, family, healthcare providers, students) are able to 'grow' and where their needs and senses are met. Conversely, impoverished environments are described as those with poor standards or care environments (Nolan, Brown, Davies, Nolan & Keady, 2006).

5.1.6 Authentic Partnerships

Models of client-centred care extend beyond the point of care to include the involvement of client-centred care at the organizational and systems level. Dupuis et al. (2010) reported on the development of the Authentic Partnership approach, a model which explores the development of partnerships with people who have dementia and healthcare providers/researchers in decision making regarding service and support delivery and development. The approach was developed collaboratively between researchers and people living with or affected by dementia. These partnerships have primarily included clients who have early to mid-stage dementia and identify the importance of having people living with dementia actively involved in decision making "to the fullest of their abilities, and support their involvement using whatever means necessary" (Dupuis et al., 2010, pg. 9).

The Authentic Partnership approach outlines the active participation of clients and their diverse perspectives in all levels of decision making (Dupuis et al., 2010). Based upon the Senses Framework, the following principles guide this work (pg. 19-21):



A genuine regard for self and others

- Recognition of and the responsibility to uphold individual rights (including respect, dignity, full engagement in life and self-determination);
- A commitment to valuing others and feeling valued, where everyone feels that they are an integral part of the process and partnership and are not being judged;
- Knowing others and allowing others to know you and, in so doing, honouring individual uniqueness; and believing in the potential of all humans for growth and development.

Synergistic relationships

- Recognition of the interconnectedness and interdependence of all citizens in communities and thus, the development of relationships characterized by interdependence and reciprocity rather than perpetuating notions of dependence and independence;
- Inclusion of a diversity of stakeholders, where all voices are valued equally; and
- Building on the diversity of the group and incorporating the gifts each partner brings to the group to generate new ideas and creative ways of doing things.

Focus on the process

- Recognition that new learning and unlearning are never ending and that we can never have all the answers or know all the outcomes or possibilities at the beginning of the process;
- Acknowledgement that flexibility and responsiveness to change are required;
- Acknowledgement that the partnership needs to be open to learning from mistakes and embraces creativity and non-traditional ways of doing things.

Enabling factors to facilitate the development of partnerships include: connecting and committing, creating a safe space, valuing diverse perspectives, establishing and maintaining open communication, and conducting regular critical reflection and dialogue. The authors report that the approach, which developed over time, has resulted in the involvement of people with dementia participating on advisory boards, advocacy initiatives, and in decision-making regarding supports and services designed for them (Dupuis et al., 2010).

5.2 Service Delivery Models

Whereas the theoretical models provide frameworks which can organize care, the service delivery models explored in this section of the review highlight the different practical approaches to client-centred care that have been reported in the literature.



5.2.1 Flexible, client-driven care

The model of flexible, client driven care, which emerged from several studies conducted by McWilliam and colleagues has been formally implemented in southwestern Ontario. The regional Community Care Access Centre (CCAC), which is responsible for the centralized coordination of home care services across the region, partnered with researchers and providers of home care services to implement the model across the region.

The model is based on the empowering partnership approach, which focuses on the evolution of a caring relationship between the healthcare provider and client and the enhanced awareness of life and health experiences (McWilliam et al., 2003; McWilliam, 2009; McWilliam et al., 1997). A caring relationship in this context is conceptualized as a 'way of being' with both the client and healthcare provider experiencing and determining how to 'be' with one another. The relationship does not have specified roles/duties; rather, it evolves. The life and health experiences of the client, rather than specific health outcomes, are the focus of the relational health-promoting process; with the initial goal being to identify, affirm and support the strengths of the clients so that these can be further developed throughout the course of the relationship. A process of relating and a mutual, conscious awareness develops through critical reflection, asking questions and integrating the knowledge of the person and the care provider (McWilliam, 2009).

In developing the approach, McWilliam et al. (1999) demonstrated that seniors receiving home care services who received usual home care plus 10 weeks of care based upon this model reported improved outcomes, including a significantly greater chance of having a higher quality of life, greater independence, greater perceived ability to manage their own health and less desire for information immediately following the intervention. At one year post intervention, the clients' level of independence and reduced desire for information remained significant.

As the model has been implemented in Ontario, further evidence has emerged. Clients have been empowered, in accordance with their knowledge, abilities, preferences and rights, to participate in decisions about care including the models of case management they prefer. The models include (McWilliams et al., 2004):

- Brokerage model A centralized case manager directs all home care services;
- Integrated team model Home care services are coordinated by a primary healthcare professional within a team environment with collaboration with the client to negotiate a plan of care;
- Consumer managed model Home care services are selected and coordinated by the client (including the required resources, direction, monitoring and adjusting of the plan of care).



McWilliam et al. (2004) revealed findings that indicated no extra costs for service delivery were incurred when clients were provided with an opportunity to identify their preferred level of involvement and service model (when compared with the control group implementing the brokerage model). The intervention also resulted in similar client outcomes for clients when compared to the control group and healthcare providers reporting improvements in the way they viewed their job. Importantly, sub-analyses confirmed that different models of case management appealed to different demographic groups, although overall, the greatest proportion of clients selected the brokerage model of care (McWilliam et al., 2004).

In 2007, McWilliam et al. reported on the findings of the analysis of a subset of data which compared the cost changes over time of the clients in each of the three models of case management, controlling for functional level, assessed need for support and client group (e.g., seniors versus adults with disabilities). The results of the analysis suggested that clients who selected the integrated care model or consumer managed model of case management were able to exercise greater independence in case management without excessive cost increases. Of the clients receiving home care services whose costs increased, those who had selected the consumer managed model of case management were found to have significantly lower increases in costs. Despite the methodological challenges for the project and limitations regarding analysis, these findings provide opportunities for health policy to consider alternative models of case management, where clients may have increased choice and input into the care they receive (McWilliam et al., 2007).

5.2.2 Front office/Back office configurations

Broekhuis, de Blok and Meijboom (2009) published a case study examining the implementation of a client-centred care model in a home care service in the Netherlands, which incorporated both a business and health perspective. Their model emphasized the role of the client at the centre of all processes and structures at the point of care, but also in all aspects of the business including: reorientation of roles, tasks, operational processes, organizational structures and inter-organizational cooperation (Broekhuis et al., 2009).

A framework outlining four approaches for the organization of back and front office tasks was developed based on their review of the literature. Front office tasks were defined as those involving direct contact and care with a client. Back office tasks were considered those where direct client care was not expected and/or required, but that contributed to the overall experience/coordination of care delivery. The authors completed process maps, examining how care was provided to clients and how clients contributed to the identification of the care required. The results highlighted that there was little opportunity for clients to be directly involved in planning their care at the organizational level. At times, where there were multiple people involved in planning care, it was suggested that the needs of the client may be lost due to the multiple handover points and the fact that there was no access point to the many services offered by the organization.



The authors reported the following solutions that were implemented to improve the provision of client-centred care including: having tasks completed by front office staff with client participation; altering responsibilities to allow more consistency in tasks completed by the same person in the front office and back office; the identification of care and service modules; and, the identification of the importance of information technology solutions to facilitate care provision and increasing efficiency of business. The study demonstrated the complexity of providing a client-centred care service within the home and community care sector and how this philosophy can be incorporated at all levels of the organization (Broekhuis et al., 2009).

5.2.3 Client-centred residential care

As an alternative to traditional nursing home-based care, Chapman, Keating and Eales (2003) reported on an innovative demonstration project conducted in Alberta, which sought to examine the experience of implementing a client-centred model of community-based residential care. This model for service was based on the following principles:

- Family members and caregivers' involvement as key care delivery partners, helping staff to learn about the client, their values and preferences;
- Redistribution of staff responsibilities in order to encompass a generalist approach to care
 provision, with staff assuming more family-like, broad duties (e.g., personal care, housework
 and other physical tasks) in order to 'get to know' the client;
- The development of a physical environment that is supportive and yet facilitates contact with the community outside of the home.

Applying the model in three different residential settings (an assisted living setting, a dementia care home and an adult family living program), the project specifically sought to explore two key challenges (pg. 254):

- Whether care that is responsive to individual values and preferences could be provided to people who were unable to take an active role in creating the fit between their needs and services; and
- Whether care can be centred in the community if people are living in residential care settings, rather than in their own homes.

Evaluation consisted of focus groups with staff and family members who had relatives receiving care at one of the centres. Three patterns related to the challenges of implementation emerged. The first challenge was engaging with others in a care partnership. Despite staff support for the client-centred care approach, many with prior experience working within nursing homes based on the traditional medical model struggled to manage when their views lacked congruence with those of the client (resident). This illustrated the importance of education and support to implement a significant change to practice.



Resource limitations, including a lack of time and physical resources, negatively impacted upon the ability of staff to develop relationships with the client and truly change practice and perceptions. Finally, there was acknowledgement of the importance of maintaining links to the community; however, the ability to actually facilitate these connections was challenged due to finite resources. As the budgets to implement these programs were reportedly less than half that of a nursing home, this funding restriction may have contributed to the shortfalls in time and resources identified through analysis (Chapman et al., 2003).

5.2.4 Patient-centred clinical method

The work of Stewart et al. (2003) has resulted in the development of the patient-centred clinical method. Originally developed in the 1980's, the model itself has evolved and is widely referenced in the medical literature; although, the authors state that the method is relevant to all healthcare disciplines (Stewart et al., 2003). Focused on the interaction between client and physician, this objective, directive model outlines 'how' to achieve client-centred care (Stewart et al., 2003; McWilliam, 2009;):

- The physician explores the patient's disease/main reason for the visit and notes four dimensions of the illness experience: their feelings about being ill, their ideas about what is wrong with them, the impact of their illness on their daily function, and their expectations about what should be done;
- Understanding the whole person: The development of an integrated understanding of the person including their personality structure, emotional needs, the contextual variables impacting their health which include those which are both proximal (e.g., education, employment and leisure) and distal factors (e.g., community, culture);
- Finding common ground regarding management: The establishment of agreed understanding of the problem and priorities, goals of treatment, and the respective roles and responsibilities of the client and physician;
- Incorporation of prevention and health promotion: Through the interaction information related to health enhancement, risk reduction, early detection and amelioration of disease are discussed;
- Enhancing the client-doctor relationship: The therapeutic relationship continues to be enhanced with sharing of power, self-awareness and consideration of transference issues;
- Being realistic: Consideration of factors which impact the provision of care (e.g., time, team work etc.).



In an article published in 2000, Stewart et al. reported on the findings of a study that evaluated the implementation of the patient-centered clinical method. It was found that this communication was correlated with the patients' perceptions of finding 'common ground' in their encounters with physicians. Achieving common ground was associated with better recovery from their discomfort and concern, better emotional health two months later, and fewer diagnostic tests and referrals.

5.3 Cognitive approaches to implementing principles of client-centred care

Although not specifically client-centred care models, the following examples reflect cognitive approaches to care that could be regarded as fundamentally client-centric and are therefore important to consider.

It can be argued that the philosophy and understanding of health or disability held by a healthcare provider can play a role in how they interact with a client. Restall, Ripat & Stern (2003) state that human behaviour is shaped by "mental models" or our "ingrained beliefs about the world and people" (pg. 105). Similarly, Cott (2004) reports that, in accordance with the symbolic interactionalist perspective, "the way that we interact with others is shaped by our perceptions of those others" (Melzer, 1972, cited in Cott, 2004, pg. 1419).

This is also reflected in work by Kitwood (1997), who suggested that there may be cultural factors which contribute to the depersonalization of those with serious illness/disability. Kitwood indicates that this may be particularly the case for clients with dementia, as those who are older and powerless may be devalued and viewed as incompetent. The presence of dementia raises fears within individuals of increasing frailty/morbidity and of mental instability, and consequently the weakening of emotional defences, leading to depersonalization. Edvardsson et al. (2008) and Cott (2004) reported that healthcare providers who view clients as 'dependent', 'helpless' or as gradually losing their 'personhood,' (in the case of dementia) are less likely to see the need for developing a caring relationship, instead delivering care that is more reflective of a medical, task-oriented approach. Conversely, if the client is viewed as retaining their personhood, autonomous and capable, then the healthcare provider may be more likely to continue relationship-building and deliver care that is client-centred (Cott, 2004; Edvardsson et al., 2008).

Developing an understanding of, and reflecting upon, the ingrained beliefs and underlying philosophy of care held by a healthcare provider may assist the provision of client-centred care. This may allow healthcare providers to separate their own perceptions, preferences and values from those of the client in order to provide care that meets the needs of clients (Restall et al., 2003; Sumsion, 2006).



6. CONCEPTS RELATED TO CLIENT-CENTRED CARE AND THEIR OPERATIONALIZATION

This section contains an exploration of the key concepts related to client-centred care that appear in the literature. The concepts that will be discussed include: power, empowerment, respect, communication, transitions and continuity and client involvement at the process and systems level of care. All of the concepts are closely related and can be considered components of client-centred care. These concepts will be investigated in terms of their broader meaning and relevance to the home and community sector; however, they will also be viewed from a broader healthcare perspective, where appropriate, to provide context to the material. The literature upon which this section is based is largely comprised of case studies and qualitative investigations. Hammell (2001) supports the use of qualitative research in the context of client-centred care, pointing out that, despite some limitations regarding generalizability, this method of investigation is particularly appropriate to gain an understanding of client-centred care and identification of client priorities. Thus, this type of research is able to provide insights which may have been overlooked if a more scientific approach had been employed (Brown et al., 2006).

To help operationalize the concepts, this section also includes examples of specific strategies that have been reported in the literature. It is evident from this analysis that client-centred care can be achieved through a number of different strategies. There is no one solution which translates to the delivery of client-centred care; rather, it is an overall approach to care.

6.1 Power

Power is a central concept in the literature regarding client-centred care and plays a role at both the process and systems level of client-centred practice (Goodyear-Smith & Buetow, 2001; Sumsion & Law, 2006), particularly within interpersonal relationships, including those of the healthcare provider and client. In the traditional, medical model of healthcare, physicians were afforded the majority of power within client/physician relationships. This was based on their access to information and technical knowledge, both of which were inaccessible to the client. The imbalance of power was actualized through the making of decisions by physicians with little, or no, client input (Goodyear-Smith & Buetow, 2001). Thus, they held 'power over' clients in this dyad (Brown et al., 2006).

The dynamics of power within the healthcare provider-client relationship have been explored in the literature, particularly in the acute care sector (Bidmead & Cowley, 2005; Goodyear-Smith & Buetow, 2001; Henderson, 2002; Hewison, 1995, cited in Oudshoorn et al., 2007). There are differing conceptualizations regarding the role of power within the client-centred care literature. Sumsion and Law (2006), for example, argue that power can provide the conceptual framework from which other components of client-centred care can be examined.



Power in this context is perceived as present in all professional (client-provider) dyads and can be understood as something that one possesses or lacks. Healthcare providers must consider the balance of power and the transferring or sharing of power (from provider to client) in order to operationalize client-centred care (Millard, Hallett & Luker, 2006; Sumsion, 2006). Once this power is shared, clients become equal partners in healthcare, as their perspectives and interpretation of illness are then taken seriously (Sumsion, 2006).

Power can also be conceptualized as an experience to be had 'with' a client. The empowering partnering approach outlines that power may emerge from a relational process existing between healthcare provider and client. Through the building of a relationship and enhanced, mutual awareness of the client (in terms of their knowledge, skills and strengths), achieved through an equitable (as experienced by the client) sharing of knowledge, status and decision making authority (including the opportunity for a client to be involved as a partner), power is achieved 'with' a client, rather than transferred to them (McWilliam, 2009).

The literature cites interventions which can be employed by healthcare providers to facilitate the 'sharing' of power with clients. The interventions selected will depend upon the healthcare providers understanding of power within the relationship. Interventions include: facilitating client participation in care, communicating with clients regarding their knowledge requirements and preferred level of involvement, facilitating clients to have increased control over their health and resources required to support this, and implementing a strengths-based approach which seeks to assist clients to identify and further develop their resources to accomplish their goals (Goodyear-Smith & Buetow, 2001; Taylor, 2003 & Rogers, 1983, cited in Sumsion, 2006; Robinson, 1991, cited in McWilliam, 2009).

Despite the acknowledgement of the importance of power and the advocacy for acknowledging power in practice, doing so remains a challenge to implement. In a study conducted by Brown et al. (2006), eight home care nurses in Ontario, Canada who were being interviewed one year post-implementation of a client-centred model of care revealed that, despite education and the opportunities which existed for client-centred practice in the home care environment, nurses were continuing to function in the role of 'expert' with little engagement of clients in practice (Brown et al., 2006).

The issue of power is relevant not only at the process level, but also at the systems level, impacting client-centred care through relationships between providers and the broader healthcare system. In a conceptual analysis of patient-centred care with a focus on acute care, Hobbs (2009) reported that in order for patient-centred care to be enacted, power must be shared between the healthcare system and providers. If healthcare providers are not allocated a reasonable amount of professional autonomy (respect and power) in their practice to provide individualized care, they may be unable to implement patient-centred care (Hobbs, 2009). This was illustrated in a qualitative study by Oudshoorn et al. (2007) which examined the role of power within client-nurse relationships in home-based palliative care in Ontario, Canada.



Through the completion of a secondary analysis of data gathered for a study exploring client–family–nurse relationships, the authors found that both nurses and clients experienced power and powerlessness within their relationship. Nurses, who had power resulting from their position as healthcare provider and relationship with the client, felt powerless within the broader context of the work environment. Clients had little positional power, but drew power from within and expressed this as control (Oudshoorn et al., 2007). Clients, however, felt powerlessness due to an inability to control the care they received (e.g., time/length of visits, continuity of care provider). The study demonstrates how the power relationships in the broader healthcare system contribute to the experience of power within the nurse-client dyad.

In their conclusion, the authors identify the opportunity nurses have to advocate for change through addressing healthcare policies, models, and funding that negatively impact care, as well as to clearly recognize the concept and experience of power in their therapeutic relationships (Oudshoorn et al., 2007). Advocating for systemic change to address power imbalances is also supported by the RNAO Best Practice Guideline "Client Centred Care" (2006), which identifies the need to address power issues within the broader healthcare organization and system by removing barriers, changing care to share power and advocating for change within existing structures.

6.2 Empowerment

Closely related to the concept of power is empowerment. Empowerment, at a process level, has been described as "a proactive, meaningful engagement in one's world" (Rappaport, 1984, cited in McWilliam et al., 2001, pg. 51) and "a fundamental way of thinking . . . that comes from within, through self-awareness and self-esteem" (McDougall, 1997, cited in McWilliam et al., 2001, pg. 51). In a broader context, it has been defined as "the participation of individuals and communities in a social action process that targets both individual and community change outcomes" (Wallerstein, 1992, cited in RNAO, 2002, pg. 13).

The sharing of power and formation of partnerships with clients is often described in the literature as the 'empowerment' of the client and is frequently cited as one of the goals or outcomes of client-centred care (McWilliam, 2009). Empowerment is an important concept both in the context of client-centred care and in home and community care, but the realization of empowerment in practice remains a challenge, with little research to date regarding how this concept can be enacted in practice (Brown et al., 2006; McWilliam et al., 2001).

In a qualitative study, McWilliam et al., (2001) sought to explore the experience of in-home care in Ontario, Canada, with a focus on the enactment of empowerment. The researchers explored the 'lived experience' of six clients, six caregivers and nine healthcare providers, finding that the experience of empowerment "was one of constrained knowledge, status and authority for all involved" (McWilliam et al., 2001, pg. 55). The researchers found that interactions within the home environment focused primarily on the limitations of the clients, reinforcing the societal norm of the sick role.



The identification and pursuit of health goals were largely determined by the system or healthcare provider, with little input from the client or consideration of their expertise (regarding goals, expectations, strengths and potential). The findings reinforced the perspective of healthcare provider as 'expert' and the creation of a system which undermines client empowerment. The authors identified opportunities to change care delivery to incorporate a more client-centred, empowering, partnership approach which respects the knowledge and strengths of the entire healthcare team (McWilliam et al., 2001).

The empowerment of people using the services of the healthcare system is one of the objectives of the consumer-directed or consumer-managed model of care. This model of service delivery, used in a number of western countries, also seeks to empower clients, who are given control over the selection, coordination and administration of various aspects of care that have traditionally been coordinated by a case manager/home care agency staff (Alakeson, 2010; Benjamin, 2001; Ottmann, Laragy & Haddon, 2009). A multitude of models have been implemented within the framework of consumer-directed care, with variety in terms of the education provided to clients in order to implement the program, client autonomy, services included in programs, target populations (e.g., clients with physical and cognitive disabilities, seniors) and the financial reimbursement available (Alakeson, 2010). Proponents of this model suggest that the traditional model of care relies upon the (home care) agencies making decisions about the care delivered, resulting in this care often meeting the needs of the agency, rather than the client (Benjamin, 2001, pg. 82). By putting control in the client's hands, the client is able to determine the scope of services required (Benjamin, 2001).

Evaluation data have revealed that clients participating in consumer-directed services have increased access to, and make use of, a greater diversity of services tailored to their needs, and report improved satisfaction (Alakeson, 2010). However, some have reported a need for case management services and further information/research to identify the healthcare outcomes/impact of the model and the most appropriate client base for these services (Alakeson, 2010; Ottmann et al., 2009).

Despite the model's objective of empowering clients, there are contradictory ideas regarding whether consumer-directed services are indeed client-centred, particularly if a client does not wish to participate in care, as true client-centred practice would not require someone to take part (Silow-Carroll et al., 2006). This is an important distinction between consumer-directed services and the model used by McWilliam et al. (2004, 2007) in which clients are offered a choice regarding the selection of the most suitable case management model to suit their needs.

6.3 Respect

The concept of respect for the client is viewed as a foundational principle supporting client-centred care (McCormack, 2003; Ontario Medical Association, 2010; RNAO, 2002). At its core, respect may be understood in terms of viewing a client as a fellow human being, as a person and respecting their values and preferences (Ross & Johansen, 2002).



A respectful relationship between healthcare provider and client acknowledges the skills, expertise and preferences of all parties. Healthcare providers remain as experts in relation to clinical care and intervention, providing and sharing valuable information with the client. Clients are acknowledged as experts regarding their body, health and healthcare goals, values, preferences and life situations (Corring & Cook, 1999; Bosman, Bours, Engels & de Witte, 2008; Brown et al., 2006; Cott, 2004). Respecting a client in this partnership is particularly relevant when there is discordance between the opinions, values and beliefs of the healthcare provider and of the client (McCormack, 2003; Nolan et al., 2004). It is in these situations that healthcare providers are challenged to consider the preferences and priorities of clients independently of their own beliefs (RNAO, 2002; Vander Henst, 1997, cited in Sumsion, 2004).

In their work exploring the perspectives of people with chronic illness and their caregivers regarding client-centred interactions with home healthcare workers, Schoot et al. (2005b) identified the emergent theme of 'recognition' as being central to the enactment of client-centred care. Linked closely to respect, 'recognition' referred firstly to clients' feeling "seen and heard, being accepted and respected and being treated seriously; secondly, recognition concerns an attitude of the professional towards the client entailing recognition of the client as a unique, comprehensive, autonomous human being, recognition that (continuity of) life and fairness are central in care, and recognition of the client as an equal, interdependent partner in care" (Schoot et al., 2005b, pg. 173). A lack of 'recognition' of the client resulted in clients feeling they were not respected, heard or taken seriously and led to feelings of frustration, anger, feeling mistrusted, inferior, insulted, humiliated, powerless, dependent and anxious; thus, negating client-centred care. The participants identified four ways in which home healthcare workers (nurses/nurses aids) could enact recognition called 'competencies.' These included: attentiveness, responsiveness, being a 'critical partner' in care and being a developer of competencies (Schoot et al, 2005b).

The provision of respect may not be operationalized in the same manner for all clients. For example, in Kitwood's model of person-centred care for clients living with dementia, respect is demonstrated through the preservation of the 'personhood' of the individual in the face of decreasing mental functioning (Kitwood, 1997). In order for respect to develop, or for 'personhood' to be understood and maintained, the healthcare provider requires an understanding of who the person is (Kitwood, 1997). This understanding can result from collaboration with the client and/or family and significant others to learn about the person, their life history, preferences and values (Epp, 2003). Strategies such as Life Story Work and narrative approaches to care have been reported in the literature as methods which can be used to learn about the client's life. Life Story Work acknowledges that what older people, including those with dementia, have to say is valuable and offers them and their families an opportunity to participate in telling their life stories, through sharing pictures, stories and memory boxes, thereby contributing to the information and knowledge of them as a person. This knowledge can then be integrated into their plan of care (Clarke, 2000; Clarke, Hanson, & Ross, 2003; McKeown et al., 2010).



Narrative approaches are also used in healthcare and are reflective of client-centred care and bio-psychosocial models. Narrative approaches use knowledge, which helps one to develop relationships based on understanding the meaning of stories through 'cognitive, symbolic, and affective means' (Charon, 2001 pg. 1898). Skills such as listening or 'bearing witness' and being empathetic are employed to facilitate the telling of stories and experiences and an exploration of their meaning, including the biological, familial, cultural and existential meanings (Charon, 2001 pg. 1898).

As an understanding of the person develops, a variety of approaches can be employed by healthcare providers to acknowledge the personhood of an individual and demonstrate respect, in a multitude of contexts. A sample of these approaches is outlined in Table 2.

Table 2 – Positive interactions in dementia care as a way to demonstrate respect at the process level of client care delivery

	Acknowledging the individual by name			
Recognition	Using eye contact			
	Verbal communication (e.g., using positive language)			
Negotiation	Consulting the individual about preferences, choices and needs			
	Respecting and honouring the client's decision			
Collaboration	Ensuring alignment between healthcare provider and client to complete tasks			
	Involving carers and friends (as per the preferences of the client)			
	Using trust building strategies to develop the relationship			
Play	Expressions of spontaneity of self			
Stimulation	Engaging in expressions using senses			
Celebration	Celebrating things that the person finds enjoyable			
Relaxation	Providing close personal comfort (holding hands)			

^{*}Adapted from Kitwood, 1999, cited in Epp, 2003

The concept of respect is also relevant at the systems level of care delivery in the relationships between providers and the broader healthcare system. In the organizational literature, respect is considered an essential core value that shapes organizational culture (Sheridan, 1992).



6.3.1 Cultural competence

In order to respect a client as an individual, including their values and preferences, attention must be given to the importance of culture. Definitions of culture are not limited to ethnicity and race; rather, culture can be defined as being comprised of "a shared system of values, beliefs and learned patterns of behaviours" (Low, 1984, cited in Carrillo, Green & Betancourt, 1999, pg. 829). The literature suggests that an understanding of a person's story, including their cultural customs and beliefs, is a key element of the client-centred approach, as this contributes to a person's experience of illness and health (Gerteis et al., 1993; Silow-Carroll et al., 2006; Sumsion, 2006). Importantly, these experiences are at the level of the person, rather than a cultural group, because even if the socio-cultural backgrounds of two people are similar, their experiences may differ dramatically (Beach, Saha & Cooper, 2006; Carrillo et al., 1999; Silow-Carroll et al., 2006).

Healthcare providers in the Canadian healthcare system provide care to clients from a number of different cultures who speak a variety of languages and have diverse social norms, socioeconomic status, and understandings of health and wellness (Carrillo et al., 1999; Gantert et al., 2008). An understanding of care within this context and cultural competence is therefore of increased importance.

In a report by Beach et al. (2006) for the Commonwealth Fund, the authors outlined the similarities between the concepts of patient-centred care and cultural competence. The authors explain that, like patient-centred care, several definitions and models of cultural competence have been proposed. These models largely include the following features: implementing a holistic approach to care that respects a person's values and cultural influences; being cognizant of cultural norms; the development of partnerships between clients and healthcare providers; and communicating effectively, while being aware of the use of language and literacy (Saha, Morse & Jimison, 2005, cited in Beach et al., 2006, pg. 8).

6.4 Communication

Fundamental to the development of a relationship between the client and healthcare provider and also in relationships between providers themselves, communication is a central component of client-centred care (Sumsion, 2006; Sumsion & Law, 2006). It is also a key factor in the provision of information and education, an essential aspect of client-centred care. A variety of communication skills are utilized to provide care which is client-centred including: verbal (e.g., use of appropriate language), non-verbal skills (e.g., body language), silence and active listening (Gage, 1998; Schoot et al., 2005b; Sumsion, 2004; Sumsion & Law, 2006).



6.4.1 Communication at the process level of client-centred care delivery

Good communication processes assist in the formation of relationships between clients and healthcare providers. These relationships can facilitate client involvement in healthcare, including the identification of values, preferences and the desired level of partnership (Gage, 1998; Avis, 1994, cited in Sumsion, 2004). According to Sumsion (2004), "open communication, including listening skills and the use of appropriate language, is important and will have an impact on the establishment of shared goals" (pg. 3).

Numerous strategies to communicate more effectively with clients and family members are cited in the medical, nursing and allied health literature. A review of guidelines for client-centred practice identified the following key communication strategies that are relevant to the home and community environment:

- Initiating discussion or strategies to help understand the client's perspective regarding his/her health and quality of life (Bauman et al., 2003; Community Research Planning and Evaluation Team, 2004; RNAO, 2002; Schoot et al., 2005b; Stewart et al., 2003; Sumsion, 2004; Wilkins et al., 2001);
- Exploring the meaning of the illness from the perspective of the person/family member (e.g., what the problem is, what may have caused it, what worries the person etc.) (Carrillo et al., 1999; Stewart et al., 2003);
- Listening to concerns, needs and questions (Bosman et al., 2008; Community Research Planning and Evaluation Team, 2004; Gage, 1998; Schoot et al., 2005b; Sumsion, 2004; Sumsion, 2005; Sumsion & Law, 2006; Wilkins, Pollock, Rochon, & Law, 2001);
- Clarifying hopes, wishes, values, preferences, strengths, needs and concerns of the client from their perspective (Bosman et al., 2008; Cott, 2004; Community Research Planning and Evaluation Team, 2004; McWilliam et al., 2001; Sumsion, 2004);
- Seeking to build the client's capacity to achieve their goals (RNAO, 2002; Schoot et al., 2005b; Sumsion, 2005);
- Acknowledging the strengths, expertise and contributions of clients (Community Research Planning and Evaluation Team, 2004; Corring and Cook, 1999; Gage, 1998; McWilliam et al., 2001);
- Assessing literacy and language skills from the perspective of the individual (Carrillo et al., 1999; Silow-Carroll et al., 2006; Wilkins et al., 2001);
- Providing information/teaching in a way that is relevant to the person and is culturally appropriate (Cott, 2004; RNAO, 2002; Silow-Carroll et al., 2006);
- Ensuring client preferences, concerns, goals and perspectives on health and quality of life are appropriately documented (RNAO, 2002);
- Demonstrating flexibility in meeting the needs of clients (Bosman et al., 2008; Community Research Planning and Evaluation Team, 2004; Schoot et al., 2006; Sumsion, 2004; Sumsion & Law, 2006; Wilkins et al., 2001);



- Acknowledging and dealing with feelings (Community Research Planning and Evaluation Team, 2004; Cott, 2004; Schoot, Hirsch & de Witte, 2007);
- Representing the client's or community's perspective for health and goals in life when communicating with the healthcare team (CAOT, 1997; RNAO, 2002);
- Communicating at regular intervals with the client, family and other relevant healthcare providers (CAOT, 1997; Cott, 2004);
- Identifying the extent to which clients want to be involved in their care (Schoot et al., 2005b).

The central importance of communication in the provision of client-centred care is further demonstrated through the work of Schoot, Hirsch and de Witte (2007), who reported on the development and evaluation of the implementation of core client-centred care competencies with home care nurses in the Netherlands. These competencies were built upon the previous work of Schoot et al. (2005a, 2005b, 2006), which examined client-centred care in the home environment from the perspective of the client and revealed the following as important characteristics of client-centred care: the provision of respect, recognition of the client demand (or client preference) for involvement, equality and partnership in care and responsiveness to client wishes (Schoot et al., 2007; Schoot et al., 2005a, 2005b, 2006).

The competencies developed were (Schoot et al., 2007, pg. 106):

Care process in dialogue

• In dialogue with the patient, the caregiver discusses the care process from the perspective of the patient and on the basis of his or her professional expertise;

Enabling client participation

• The caregiver assists the patient in formulating his or her questions and wishes with respect to entire care provision and encourages the patient to take control of the care process;

Dealing with tensions

The caregiver is able to deal with any problems and contentious issues that may arise. The
caregiver actively seeks out alternative options in the event of tensions between the client
perspective and professional, individual and organizational responsibilities.

The authors evaluated the implementation of these competencies, concluding that the skills required for implementation of the competencies could be developed by nurses through a comprehensive training module. Importantly, however, they found that client-centred care as a whole needed to be "embedded in the attitude, policy, structures and processes at all levels of the care organization" in order to be fully realized in practice (Schoot et al., 2007, pg. 116).



6.4.2 Language

The use of language in the provision of client-centred care is an important element of practice when communicating with all clients (Sumsion, 2006; Sumsion & Law, 2006). Research suggests that when language barriers exist, there may be less interaction between clients and healthcare providers, resulting in communication challenges. Clients may not make comments or ask questions and healthcare providers may not address them (Rivadeneyra, Elderkin-Thompson, Cohen Silver & Waitzkin, 2000). In a study conducted by Norris et al. (2005), healthcare interpreters recommended that to address communication barriers, healthcare providers use lay language, avoid making jokes (which may be culturally inappropriate) and use non-verbal methods of client education. Furthermore, evidence suggests that clients experiencing language barriers may benefit from the use of healthcare interpreters (Norris et al., 2005), although their use may inhibit some important aspects of client-centred care such as relationship building, due to reduced time and interaction with the healthcare provider (Rivadeneyra et al., 2000).

Even where there is congruence between the language spoken by the healthcare provider and client, the 'language' of health may still act as a barrier. The term 'health literacy' is used to describe "the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course" (Rootman & Gordon-El-Bihbety, 2008, pg. 11). Health literacy incorporates a number of skills including document literacy, prose literacy, and numeracy skills (Canadian Council on Learning, 2008, pg. 10). It requires knowledge about the body, healthy behaviours and the broader healthcare system. Approximately sixty percent of Canadian adults lack the health literacy skills to adequately manage their health and healthcare needs (Canadian Council on Learning, 2008). Certain groups of people appear to be more likely to experience challenges regarding health literacy including: older adults, minority populations, those with low economic status and medically-underserved populations (U.S. Department of Health and Human Services, 2010).

In order for care to be client-centred, healthcare providers must be aware of the skills and knowledge required by clients in order to communicate effectively, including awareness of the importance of using appropriate language (Gerteis et al., 1993; Sumsion & Law, 2006). This is important as the language of healthcare holds significant meaning in the relationship with the client and, when it is not understood by clients, can be demeaning (Siefert, 1992, cited in Pedlar et al., 2001). In order to address this, healthcare providers should attempt to use language which is simple, inclusive and facilitates participation. In addition, enquiries should be made to ensure that clients have understood the information shared with them (OMA, 2010; Sumsion, 2006).



6.4.3 Education

The role of communication in client-centred care is essential not only in the development of a relationship with a client, but also in the provision of information and education to clients. Healthcare providers who do not provide sufficient or consistent information about conditions and/or treatment options and a lack of client involvement in treatment planning have been shown to be significant causes of client dissatisfaction (Community Research Planning and Evaluation Team, 2004; Grol et al., 2000 and Coulter & Cleary, 2001, cited in Coulter, 2003). There is also strong evidence to suggest that appropriate education can play an important role in outcomes, with research demonstrating that clients who are well informed about their condition, including their treatment options, are more likely to follow the agreed-upon treatment plan (Marinker, 1997, cited in The King's Fund, 2010). This is supported by literature, which cites that clients fared better following discharge if they were adequately informed about their illness, the goals of the treatment and the importance of aftercare (Sullivan & Yudelowitz, 1996, cited in Sumsion, 2004). It is therefore important for healthcare providers to consider each client's culture, traditions (including alternative/folk remedies) and language, so that the information and education is provided at the level that is required by the client and in a way that they understand (Silow-Carroll et al., 2006).

Evidence suggests that providing information and education to clients is of most value when it is interpreted to be relevant to their individual circumstances (The King's Fund, 2010). This interpretation can help clients understand the information, enabling them to manage their health and recall the information provided more readily (McPherson et al, 2001, and Diabetes UK, 2009, cited in The King's Fund, 2010). Importantly, the timing and type of information that is required by a client may vary and they may require different types of information at different stages of the illness trajectory (Cott, 2004). Therefore, tailoring the information and education provided, in partnership with clients, is an important aspect of client-centred care provision (Cott, 2004). Furthermore, as sharing knowledge can assist clients to obtain, process and understand health information, the active participation of clients in their healthcare and informed decision making (Coulter & Ellins, 2006), is another way that healthcare providers can facilitate the sharing of power within the client relationship (Sumsion & Law, 2006).

6.4.4 Communication at the systems level of client-centred care delivery

The importance of communication at a systems level is highly relevant to the home and community setting, in which care is provided to clients by a multi-disciplinary team. A team has been described as "a small number of people with complementary skills who are committed to a common purpose, set of performance goals, and approach for which they hold themselves mutually accountable" (Katzenbach & Smith, 1993, cited in Sevin, Moore, Shepherd, Jacobs & Hupke, 2009, pg. 25).



The collaboration of healthcare providers in the provision of quality care for clients is emphasized in reports regarding the need for integrated healthcare services and teams (Abendstern, Reilly, Hughes, Venables & Challis, 2006; Cott et al., 2008; Gage, 1998; Sommers, Marton, Barbaccia & Randolph, 2000; Spragins & Lorenzetti, 2008). Similarly, the need for the Canadian healthcare system to concentrate on interprofessional collaboration in education and practice has been acknowledged, with significant resources directed towards improvements, in an effort to enhance client-centred care across the healthcare system (Gilbert, 2005).

The ability for teams to function effectively within the home and community setting has the potential to impact both client-centred practice and particularly the continuity of care. Sumsion and Lencucha (2009) identified that interdisciplinary dynamics, such as cohesion, consultation and role clarity, contribute to the provision of client-centred care. Risks to the execution of client-centred care in the home and community sector, particularly to the continuity of care, have been reported to occur if there is ineffective communication (e.g., documentation), professional territoriality and ambiguous role responsibilities (Street & Blackford, 2001 cited in Gantert & McWilliam, 2004; Pateman, Wilson, McHugh & Luker, 2003). This is particularly relevant given research findings that highlight the challenges of collaboration in the home and community context. Cott et al. (2008) conducted a study examining the inter-relationships between seniors living in the community with arthritis, their carers (family members) and healthcare providers in Ontario, Canada. Results indicated a lack of collaborative practice, with the majority of participants identifying that no collaboration occurred between team members. Communication tended to occur in a discipline-specific manner, primarily between the provider and individual patient.

The complexities of interdisciplinary teams in the community were highlighted further by a qualitative study conducted by Gantert and McWilliam (2004), which sought to examine the workings of community-based interdisciplinary teams. The study revealed that the teams were largely virtual, loosely knit, and had a dynamic association with one another and highlighted the need to provide practical assistance and strategies to facilitate teams' "fulfillment of their shared responsibilities and accountabilities" (pg. 14). The importance of communication and collaboration in the multi-disciplinary team environment of the home and community sector appears to be an area where opportunities exist to improve client-centred practice. New developments in terms of technology, explored in the next section of the review, may assist in providing new and innovative strategies.



6.5 Transitions and continuity of care

A transition is the experience of moving between locations of care from one sector of the healthcare system to another. There is an increased risk for clients to experience fragmented care across these 'transition' points within the system, where there may be a lack of continuity of care plans, communication, systems and processes, which could result in a poor experience and safety risks (Coleman, Smith, Frank, Min, Parry & Kramer, 2004; Pateman et al., 2003). In addition, care management approaches for clients as they navigate a transition have been found through exploratory research to be disempowering for clients and resulted in the fostering of dependence (McWilliam, 1992 and McWilliam et al., 1994, cited in McWilliam et al., 2004). Furthermore, poor transitions can result in increased hospital and emergency service use, thereby increasing the costs of healthcare (Coleman et al., 2004).

In Cott's exploration of client perceptions regarding client-centred rehabilitation care (2004), the importance of preparing clients for transitions was identified as a key element of client-centred care. Clients expressed concern regarding their transition from the inpatient rehabilitation environment, where they received care and were viewed as a 'patient', to the community, where they would transition to life as a person with a disability who would require skills to return to functioning in that setting (Cott, 2004).

Several strategies to promote client empowerment at transition points have been proposed in the literature. For example, a coaching and empowering approach has been implemented to assist and educate chronically ill clients and their carers to advocate for themselves, ensuring their needs are met during transition periods. Called the Care Transitions program, this approach has resulted in reduced rates of subsequent re-hospitalization and high levels of patient investment in the program (Coleman, Parry, Chalmers, & Min, 2006; Coleman et al., 2004; Parry, Coleman, Smith, Frank, & Kramer, 2003; Parry, Kramer, & Coleman, 2006).

The concept of continuity of care has been raised throughout the literature as an important element of client-centred care (Bosman et al., 2008, Cott, 2004; Gantert et al., 2008; Gerteis, 1993). A 2004 study conducted by Woodward et al. examined the factors that were important to the experience of continuity of care in home care in Ontario, Canada. Interviews were conducted with clients, caregivers, healthcare providers in the home care system and physicians whose clients received home care. The results indicated that continuity of care was experienced when care ran smoothly, was responsive to clients' needs and required no special effort on the part of the client to maintain (pg. 180). Communication and consistent personnel were identified as key components to achieving continuity. This was supported by Bosman et al. (2008) who found that home care clients wanted more control over the members of the team who came into their home, preferring continuity of staff. Continuity facilitates communication, which, in the home and community care sector, can be challenging due to the decentralized and isolated nature of practicing within the community (Spiers, 2002).



A steady team of healthcare providers can help to facilitate contributions from all members of the team (including the client) into the plan, execution and renegotiation of the care and remove some of the challenges of communication in this environment (e.g., lack of information conveyed from one provider to another). Finally, continuity of care was found to help build trusting relationships between clients and healthcare providers, as the healthcare providers became more knowledgeable and informed about the specific clinical situation of the client (Woodward et al., 2004; Bosman et al., 2008). It also allowed for the client and healthcare provider to negotiate issues which were important to the client, such as the timing of service provision (Woodward et al., 2004).

Models such as the Patient Centred Medical Home (PCMH), utilized in the United States, which focus on the provision of continuity of care, are gaining increasing prominence in practice and a growing evidence base. In the medical home model, responsibility for the coordination of care resides with one of several healthcare team members who collaborate to provide care for a client at all stages of life, from prevention services to end-of-life care (Rosenthal, 2008). This model takes an individualized approach, with members of the healthcare team re-forming over time based on the changing needs of the client and his/her family. Members of the multidisciplinary healthcare team may include: primary care physicians, specialists, nurses, social workers, care managers, dieticians, pharmacists, physical and occupational therapists, family, and community (Rosenthal, 2008, pg. 427). A variation of the model has been implemented in the Ontario healthcare system in the form of Family Health Teams (FHTs) which began operation in 2004. These multidisciplinary care teams work with clients to identify and address their healthcare and social needs, through an integrated, holistic approach to care (Rosser, Colwill, Kasperski, & Wilson, 2010). The interdisciplinary nature of these approaches to care highlights the need for teamwork and collaboration in order to provide clients with care that is truly client-centred.

6.6 Client participation in care

The role of client participation in healthcare emerged from the literature as a key aspect of client-centred care. It is supported by the World Health Organization in the Declaration of Alma-Ata (1978) which states that "people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare" (pg.1).

The literature reflects participation at two major levels: the point of care between clients and their healthcare providers, and at the systems level, through involvement with the broader healthcare programs/policies and services.



6.6.1 Participation at the point of care

Similar to the concept of client-centred care, the literature regarding participation is acknowledged as having multiple, similar terms used interchangeably within the discourse (Cahill, 1998). Terms such as collaboration, involvement, and partnership are often used interchangeably with participation (Cahill, 1998). In a widely referenced conceptual analysis of patient participation by Cahill (1996), the author suggested a hierarchical framework to differentiate between these terms. In this framework, client involvement/collaboration is viewed as the most attainable, followed by participation, and then client partnership, which is described as "an ideal, a goal towards which all practitioners should be working" (Cahill, 1996, pg. 567).

The concept of participation is explored by a variety of disciplines (e.g., medicine, nursing, occupational therapy), each bringing a slightly different perspective to the process (Bauman et al., 2003; Cahill, 1998; McWilliam, 2009; Levesque et al., 2010; McCormack, 2004; Millard, Hallett, & Luker, 2006; Oudshoorn et al., 2007; Sumsion & Law, 2006). Within the home and community literature, participation at the point of care is presented in a number of different ways, including: a relationship or partnership with a healthcare provider, shared decision making, goal setting and/or self-management of care. These are explored in greater detail below.

6.6.2 Client-Healthcare provider relationships and partnerships

The concept of relationship plays an important part in participation and a number of conceptual analyses of partnership are reported in the literature. For example, Hook (2006) concluded that the attributes of partnership include relationship, power sharing, shared decision-making and patient autonomy and views partnering as occurring 'over time'. Gallant, Beaulieu and Carnevale (2002) refer to the patient/nurse relationship as a partnership and explore the manner in which partnerships are actualized. They identify the main attributes of partnership as the structure of the relationship, power sharing and negotiation. Importantly, although a relationship between a client and healthcare provider may be established, a client may still elect not to pursue an active partnership in their care. A relationship therefore, does not denote a partnership (Gallant et al., 2002). In the home and community setting, a conceptual analysis of partnership in the context of home visitors in the UK by Bidmead and Cowley (2005) describe partnerships as "...a respectful, negotiated way of working together that enables choice, participation and equity, within an honest, trusting relationship that is based in empathy, support and reciprocity...." (pg. 208). Following their search of the partnership literature in health visiting, paediatric and general nursing, the authors identified the following attributes of partnership:



Figure 1 - Defining Attributes of Partnership

- 1. A genuine and trusting relationship.
- 2. Honest and open communication and listening.
- 3. Praise and encouragement.
- 4. Reciprocity.
- 5. Empathy.
- 6. Sharing and respect for the other's expertise.
- 7. Working together with negotiation of goals, plans and boundaries.
- 8. Participation and involvement.
- 9. Support and advocacy.
- 10. Information giving.
- 11. Enabling choice and equity.

In a 1997 study, McWilliam et al. evaluated the implementation of a holistic, interactive process where a client and healthcare provider developed both a caring relationship and enhanced conscious awareness of life and health experiences. Through analysis of interviews between 13 clients with chronic conditions and a home care provider, the findings indicated that a relationship developed through "understanding the individual's situation and situatedness; active listening, unconditional positive regard, non-judgemental responsiveness and continuity of relationship" (pg. 118). This caring relationship was thought to contribute to the empowerment of the client to achieve their health goals (McWilliam et al., 1997). This was followed by a randomized control trial by McWilliam et al. (1999), which evaluated the effects of client participation in a reflective dialogue process in the home environment. The health promotion intervention, delivered by a nurse for an average of 10 hour-long sessions, resulted in decreased service usage and fewer days in hospital. Furthermore, the intervention group reported improvements in quality of life, perceived ability to manage their own health, independence and significantly lower unmet informational needs. Importantly, lower unmet informational needs persisted for one year following the intervention.

The perceptions of senior clients of their relationships with home care providers in southwestern Ontario were examined by Gantert et al., (2008). In contrast to previous studies, the researchers found that seniors were active participants in the development of relationships. The authors identify a number of strategies that could help healthcare providers to facilitate the development of a relationship between themselves and seniors receiving home care, such as ensuring reciprocity in the nurse/client relationship and the importance of getting to 'know' the person receiving care (beyond the physical or presenting issue). Additionally, the study identified 'contextual factors' that impacted on the development of partnerships, such as time and consistency in the providers, which can either facilitate or hinder the relationship building process (Gantert et al., 2008).

^{*}From Bidmead & Cowley, 2005, pg. 206. Reproduced with permission.



The importance of time in the development of a client–healthcare provider relationship appeared frequently in the literature (Gage, 1998; Gantert et al., 2008; Hook, 2006; Oudshoorn et al., 2007; Sumsion & Law, 2006). This is important, particularly in the home and community context, where, as pointed out by Spiers (2002), nurses are required to "quickly develop a trusting relationship in which nursing interventions are tailored to unique needs within the patient's individual context" (pg. 1033). Both the home and community and broader literature frequently cite a lack of time as a limitation or challenge of practicing in a client-centred manner (Brown et al., 2006; Gage, 1998; Gantert et al., 2008; MacLellan & Berenbaum, 2007; RNAO, 2006; Sumsion & Lencucha, 2009; Wilkins et al., 2001; Wressle & Samuelsson, 2004). The concept of time, and the notion that a relationship develops over time, is therefore closely related to the importance of consistency in provider, as this consistency allows for greater time for the client and healthcare provider relationship to develop (Ross & Johansen, 2002).

The concept of power is also raised in terms of the formation of partnerships and, as discussed in section 6.1, can be contextualized in different ways, such as sharing of power 'with' or 'between' the healthcare provider and client, developing it together or holding power 'over' (Cahill, 1996; Gage, 1998; Gallant et al., 2002; Hook, 2006; Millard et al., 2006; Oudshoorn et al., 2007). In order for a relationship to develop, healthcare providers must be aware of power influences on the dynamics of relationships, both in the relationship with the client and with other providers (Brown et al., 2006; Gage, 1998; McWilliam, 2009; Sumsion & Law, 2006) Gage (1998) reports on the development of 'synergistic relationships' between the entire treatment team (which includes the client) and identifies certain conditions that are required to set the foundations for these relationships. Within the healthcare provider-client relationship, the author emphasizes the importance of communication, particularly listening (being in an appropriate environment, demonstrating that the receiver of a message has 'heard' its meaning and listening empathetically), mutual trust in skills/ability, getting to 'know' one another and seeing the person holistically, as more than their illness or problem for the development of relationships.

The challenges of realizing partnerships in the home and community sector have been documented and it is unclear from the literature whether partnerships between healthcare providers and clients/caregivers are consistently being established in clinical practice (Borg et al, 2009; Gantert et al., 2008; Hamalainen et al., 2003; Millard et al., 2006). In an observational study, for example, that examined client involvement in community nursing care, the observation of 137 interactions with 22 nurses and 107 clients revealed that there was significant variation in the degree to which nurses supported client involvement in care (Millard et al., 2006). This variability was detected not only between nurses, but also within the practice of individual nurses. The authors suggest that the degree of client involvement may be related to not only the attitudes of individual nurses, but also to the relationship that exists between the nurse and client.



Proposing an 'involving to non-involving continuum,' the authors outline five typologies for this relationship identified in the study, which are explained in greater detail in Figure 2. Each typology involved varying degrees of social and professional dimensions, which helped to shape the content of the interaction. The social dimension facilitates an interaction where the nurse and client were equal partners, one which focused attention on the relationship, rather than the 'task at hand'. The latter focus was noted in interactions that had a primarily professional focus. This focus removed the ability to develop a relationship outside the nursing task and served to reinforce traditional, non-participatory ways of interacting. The findings, while informative, must be interpreted carefully, as the study was conducted with a small sample of nurses within the British context and provided no information regarding the demographic information of the clients involved (Millard et al., 2006).

Figure 2 – Involving to non-involving continuum

Completely involving	Partially involving	Forced involving	Covert non-involving	Overt non-involving
Nurse invites the patient to participate in making all decisions about all aspects of care.	Nurse invites the patient to participate in making decisions about some aspects of their care.	Nurse invites the patient to participate in making decisions after being challenged by the patient.	Nurse does not invite participate in making a. at all b. after seeking, or be patient's opinion	decisions, being given, the

^{*}From Millard et al., 2006, pg. 147. Reproduced with permission.

In a study conducted in the Netherlands, Schoot et al. (2005a) examined the interactions between nurses and clients in the home and the extent to which they were client-centred. They discovered that within the nurse-client relationship, there were a myriad of patterns of interaction (see Table 1 above). The type of relationship that developed was based on the client's preferences, the amount of participation 'allowed' by the nurse and the client's competencies (cognitive abilities, age, energy, knowledge, etc.). Different types of interactions could occur within one episode of care. Importantly, the level of involvement was not associated with client perceptions of client-centredness; rather, it was the congruence between the client's preferences regarding the desired and allowed level of involvement that was important.



In an effort to facilitate the involvement of home and community care clients in practice, various tools and assessments have been developed to assist with the formation of partnerships; however, their effectiveness does not appear to have been evaluated (Kane, Degenholtz & Kane, 1999; Lévesque et al., 2010; Mitcheson & Cowley, 2003). A small study conducted by Mitcheson and Cowley (2003), which used conversational analysis to assess an instrument designed to help identify client needs and enable them to participate in care, found that the use of such an instrument by home care providers in the UK actually reinforced the healthcare provider as 'expert' and minimized the importance of interpersonal relationships and communication. In contrast, a study by Lévesque et al. (2010), which explored the experiences of caregivers and home care practitioners (nurses and social workers) using a tool to facilitate partnerships, revealed that the tool increased the practitioners' recognition of caregiver issues and helped to involve them in care.

6.6.3 Shared decision making

Shared decision making is closely related to the concept of partnership and can be an outcome of client participation in care. It can be defined as the "collaboration between the healthcare provider and the patient, through two-way communication and information exchange, to come to an agreement about a treatment decision" (Chow et al., 2009, pg. 5). In a large, evidence-based review of shared decision making by Chow et al. (2009), the authors summarise the reported benefit of the process including: improved knowledge and recall, the generation of realistic expectations about the benefits and harms of treatment, reduced decisional conflict, an increased role in decision making without an increase in anxiety, increased patient engagement, and empowerment (Chow et al., 2009, pg. 18).

Shared decision making affords the client a level of autonomy within the relationship to take an active part in the decision making process (Bauman et al., 2003). However, this autonomy raises the potential for discrepancies to exist between client preferences for treatment and the interventions found to be effective through research, chart reviews, clinical experience, etc. (Sidani, Epstein & Miranda, 2006). When clients are empowered to make decisions regarding their own care based on their values and preferences, their decisions may be discordant with the perspective of the healthcare provider and with the recommended evidence from other sources, which can cause distress for the care provider (Bauman et al., 2003; Litchfield & McDougall, 2002; Morgan & Moffat, 2008).

Importantly, shared decision making and evidence-based practice are not mutually exclusive and clients' values and preferences are considered forms of evidence that can inform practice (Sumsion & Law, 2006; Sackett et al., 2000, cited in Sumsion & Law, 2006). Sidani et al. (2006) are also supportive of this consideration of client values/preferences and proposed a model to integrate evidence-based practice and client-centred care, in which implementation is comprised of three discrete steps:



- 1. Synthesis of valid evidence about the effectiveness and relevance of interventions to address a specific clinical problem;
- 2. Clients are informed of all available, evidence-based interventions through the generation of written material describing these; and
- 3. Selection and implementation of care based upon the identified patient preferences.

This is reflective of the three basic steps outlined by Chow et al. (2009) for the facilitation of shared decision making: information exchange, deliberation, and decision; however, Sidani et al.'s work emphasizes the consolidation of evidence.

The determination of client values and treatment preferences within this broader context of care was highlighted by McCormack and Loewen (2007) who reviewed five sets of Canadian chronic care Clinical Practice Guidelines and found that only three of the five mentioned the role of patients' values and preferences in decision making. None of the guidelines provided substantive information that could be used by the clinicians to discuss treatment benefits and risks with clients. This demonstrates room for improvement in terms of system wide implementation of a shared decision making framework in care.

There has, however, been considerable work conducted to support informed decision making through the use of patient decision aids. These tools provide a method of facilitating shared decision making by providing clear information to clients about care, including options for treatment, side effects and outcomes. In addition, patient decision aids can assist people to weigh options against their own personal values. Decision aids have been shown to improve clients' knowledge, provide them with more realistic perceptions of potential benefits/harms and facilitate researching decisions that reflect client values and preferences with greater ease (O'Connor et al., 2009).

Despite the evidence supporting the use of shared decision making as a means of achieving client-centred care, some clients may not prefer a client-centred approach (de Haes, 2006; Wilkins et al., 2001) and may elect not to participate in shared decision making. They may instead prefer to defer to the healthcare provider as expert and/or prefer not to receive information about all of the available options for them in terms of treatment (de Haes, 2006; Wilkins et al., 2001). This returns to the concept of communication and respect for the clients' values and preferences and the need to honour these preferences in care.

6.6.4 Goal setting

A closely related concept to partnerships in care and the act of shared decision making is that of goal setting. The identification of goals that are both relevant and important to the client, features particularly in the rehabilitation and occupational therapy literature, as both an important element of client-centred care and as a means of motivating clients to participate in their care (CAOT, 1998; Cott, 2004; Malec 1999, Pollock, 1993, Shut & Stam, 1994, cited in Doig, Fleming, Cornwell, & Kuipers, 2009).



As a means of facilitating client-centred care, goal setting assists clients to identify their goals for care based on their perceptions and priorities (Pollock, 1993, cited in Doig et al., 2009). The setting of goals involves the client and healthcare provider working together to develop a shared understanding of the values, preferences and priorities of the client and integrate this into the plan of care. The accomplishment of these tasks can be facilitated by communication skills (e.g., listening skills and appropriate use of language) especially in terms of setting the context for client-centred practice and the identification of goals that are relevant to the client (Sumsion, 2004).

The importance of goal setting in the home and community context was identified in research by Cott (2004), where clients viewed their participation in the identification of goals as an important element of client-centred care. Concordance between the goals set by the client, the family and the healthcare team has also been shown to be an important element of client-centred care (Sumsion & Lencucha, 2009). Furthermore, a discordance between healthcare provider and client goals has been identified as a significant barrier to client-centred practice (Sumsion, 2004; Sumsion & Smyth, 2000; Wressle & Samuelsson, 2004), which is explored in greater detail in Section 8.

6.6.5 Self-management in chronic disease

The concept of goal setting and the use of shared decision making to establish treatment plans are two components of self-management, which has become an increasingly popular strategy within the healthcare community, particularly as the prevalence of chronic conditions have increased (Bauman et al., 2003; The King's Fund, 2010). Self-management programs empower clients to make choices and decisions regarding how to manage their health and wellness (The Kings Fund, 2010). A comprehensive review of self-management programs is beyond the scope of this review; however, the concept is important when considering client-centred care within the home and community sector, as it provides a clear example of partnerships between healthcare providers and clients where power is shared.

6.6.6 Client participation at the organizational and systems level of client-centred care delivery

There is significant support in the literature for the engagement of clients at the level of service/program delivery within organizations and at the broader systems level (Cott, 2004; Pivik, 2002; Ponte et al., 2003; Shaller, 2007; Silow-Carroll et al., 2006; Wilkins et al., 2001). Client and citizen participation in healthcare is often reported as an ethical and democratic right, which can lead to enhanced client-centred service provision and improved service quality (Bruni, Laupacis & Martin, 2008; Crawford et al., 2002; Pivik, 2002). Client and public participation is therefore a topic generating great interest from government (Bruni et al., 2008; Pivik, 2002), researchers, (Crawford et al., 2002; Nilsen, Myrhaug, Johansen, Oliver & Oxman, 2006) and clients (Corring & Cook, 1999). However, the extent to which client and the public participation has been realized in Canadian practice has been questioned (Bruni et al., 2008; Tritter & McCallum, 2006).



Client participation at the level of the organization may include involvement in activities such as quality improvement projects, client and family councils and the delivery of specific programs (Crawford et al., 2002). There is a significant amount of literature regarding the integration of clients into the work of acute care organizations (e.g., Ponte et al., 2003; South Australian Department of Public Health, 2000); however, an in-depth examination of this material was outside the scope of this review.

Within the community context, extensive work has been completed in the mental health sector where involvement of clients in mental health services is supported in policy both within Canada and internationally (Tobin, Chen & Leathley, 2002). The extent of involvement was demonstrated by Grant (2007), who examined the prevalence of client participation in mental health organizations' planning, evaluation, employment, governance, hiring and training in Ontario, Canada. Data were gathered by sending the Consumer Participation Questionnaire to 168 organizations within the province. Results indicated that the 74 mental health organizations that responded had integrated clients in a variety of roles within their organizations. Examples of engagement with the organization (as reported from highest to lowest) included involvement in planning, policy development and hiring, membership on Boards of Directors, and clients attending and conducting staff training. The number of clients who were employed by the organization was difficult to determine due to selection bias (e.g., a number of the organizations included in the survey were client based 'survivorship' organizations).

The integration of clients in the work of organizations at the program/service level has also occurred within the community sector, outside the area of mental health. Leonhardt, Bonin and Pagel (2006) reported on the establishment of a Patient and Family Safety Council in Walworth County, Wisconsin, coordinated by a private company, Aurora Health Care. Typically used in the acute care or healthcare system setting to engage with clients, this model was implemented in this community setting with the aim of developing interventions, which integrated the perspectives of clients, to support medication safety in the community.

There are also examples of how clients have been engaged at the organizational level within the home and community by leading or managing programs independently or with minimal health provider intervention. Examples of this include consumer run drop-in centres or clubhouses for clients with mental illness (Mowbray, Woodward, Holter, MacFarlane & Bybee, 2009), community leg ulcer clubs (Lindsay, 2006) and/or peer-led self-management programs (Wilson, 2008).

Client involvement at the broader healthcare system level is supported both within Canada and abroad (Bruni et al., 2008), and was recognized by the Romanow Commission (2002). Participation at this level can include an array of activities, such as participation in the development of healthcare policy and research, health service development and planning (e.g., identification, development and evaluation of services) (Daykin, Sanidas, Tritter, Rimmer & Evans, 2004; Boote, Telford & Cooper, 2002; Bruni et al., 2008; Restall & Strutt, 2008), development of clinical practice standards (Beal et al., 2007), and education of healthcare providers (Young et al., 2005).



Methods of involvement can include one-time consultations, participation on advisory committees, participation in quality improvement projects, and research, amongst others; however, there is no consensus on the most effective methods for engaging clients to participate at this level of healthcare.

The rationale for client participation in publicly funded healthcare services at the healthcare system level has been outlined by Bruni et al. (2008) and includes:

- The public is the key stakeholder in the healthcare system, as it is publicly funded, and therefore should have a role in key decisions;
- Public engagement supports the principles of a democracy;
- Contributing to decisions fosters support for the decisions and helps to increase levels of trust and confidence within the system;
- Client participation ensures the perspectives and values of the community are integrated into the system.

Reviews to evaluate the effectiveness of client involvement at the systems level on healthcare decisions, effects on use of service, quality of care or satisfaction have been inconclusive due to a lack of available evidence (Crawford et al., 2002; Nilsen et al., 2006). Additionally, a Cochrane review published by Nilsen et al. (2006) did not find a 'gold standard' method of engaging and integrating client perspectives.

Several potential barriers to public involvement have been identified, including lack of representativeness, bias (Boote et al., 2002; Bruni et al., 2008; Daykin et al., 2004), perceived limitations on users' knowledge and experience (Daykin et al., 2004; Bruni et al., 2008), poor communication between healthcare providers and "users" (Daykin et al., 2004) and increased costs (Boote et al., 2002). In addition, a key challenge to the inclusion of clients at this level of healthcare is the reactions and perceptions of healthcare providers who may feel threatened or uncomfortable (Wright & Rowe, 2005). In an article exploring the underlying causes for resistance to user involvement in occupational therapy, Wright and Rowe (2005) propose that this has stemmed from concerns regarding professional identity, citing the struggles that professionals face in terms of fitting within a multidisciplinary team framework.

In 2008, the Institute for Patient and Family-Centered Care collaborated with the Institute for Healthcare Improvement to develop a set of recommendations and promising practices regarding partnering with clients to design a client-centred healthcare system. During a one-day meeting, over 100 client advisors, administrative and clinical healthcare leaders and quality improvement employees worked together to develop the following key recommendations for organizations in order to assist them with proceeding in developing partnerships with clients (Johnson et al., 2008, pg. 1):



- Inform and convince policymakers, administrators, healthcare providers, educators and clients of the importance and value of partnerships with clients;
- Offer opportunities for healthcare administrators, educators and providers to learn practical strategies for implementing client-centred care;
- Employ client leaders in meaningful positions in the healthcare system;
- Work with community groups to educate clients to expect partnerships in their own healthcare and meaningful roles in healthcare institutions and the healthcare system;
- Enlist accrediting bodies in developing standards related to partnerships with clients and client-centred care;
- Enlist purchasers and payers in expanding their definition of quality to include outcomes that reflect client-centred practices and to utilize such criteria in payment.

Despite the reported value of client participation in the quality improvement of healthcare and health outcomes, there is currently a need to further develop the evidence base to support the success of specific strategies (Johnson et al., 2008; Tobin et al., 2002).



7. TECHNOLOGY AND CLIENT-CENTRED CARE

The literature review revealed a great body of knowledge in the area of technology as it relates to client-centred care. Technology is of particular importance in the home and community sector as it helps to facilitate care delivery in this environment. To manage the abundance of literature on this topic, the following themes were identified as they relate to client-centred care and technology within the context of home and community care: client engagement and empowerment, the potential of technology to facilitate client-centred care, chronic disease management, telehealth, barriers to the use and implementation of technology, and the electronic health record.

7.1 Client engagement and empowerment through technology

When examining the shift toward client empowerment and client-centred care, the impact of technology cannot be overstated. Increases in the adoption and use of technology by both the public and healthcare professionals have changed the dynamic of healthcare in which clients are increasingly becoming active and empowered consumers of health information (Bruegel, 1998; Atienza et al., 2010). In fact, electronic access to information and e-health applications are seen as the key to enabling client empowerment and client-centred care (Bruegel, 1998; Hesse, 2007 in Atienza et al., 2010).

Social, economic and technologic trends are combining to make the empowerment of clients an increasingly powerful factor in the delivery of home care (Bruegel, 1998). As a result, an ideal client care experience is now considered one in which all systems and processes are geared to meet the needs of the client: a safety-oriented system that provides standardized, evidence-based care supported by technology, but that recognizes and responds to individual needs (Gold, 2007).

7.2 Potential of technology to facilitate client-centred care

Numerous documents suggest that emerging technologies can make client-centred care more easily attainable (Moore & Wasson, 2006; Russo, 2001). For instance, technologies such as automated registries and client portals greatly expand the opportunities for productive interaction between clients and healthcare professionals (Walters, Barnard & Paris, 2006; Bu et al., 2007). Through portals, clients can participate in administrative actions such as appointment scheduling, medication refills or billing, as well as clinical issues such as correction of medications and review of test results. Clients can also review their medical record and add information to it about issues that matter to them. Client portals offer incredible potential to supplement the face-to-face practitioner-client relationship, and to enable clients to become better informed and more empowered participants in their own healthcare (Walters, Barnard & Paris, 2006). Moore and Wasson (2006) note that when clinicians take seriously what matters to clients and the clients receive information tailored to their needs, there is improvement in care.



Atienza et al. (2007) highlighted the benefits of technology with respect to disease prevention and control. Increased use of the internet can facilitate information acquisition; tailored dissemination of health information; academic, commercial and governmental collaborations; the adoption of healthy lifestyles, such as changes in diet, physical activity, weight and smoking; detection and treatment of disease; and community outreach. Bu et al. (2007) created a computer model to project the impact of information technology (IT) enabled disease management on care processes, clinical outcomes and medical costs for clients with type 2 diabetes. They found that IT-enabled diabetes management has the potential to improve care processes, delay diabetes complications and save healthcare dollars.

7.3 Chronic disease management

The aging population, rising healthcare needs and the availability of new technologies are creating great possibilities for the collaboration of chronic disease management and home healthcare. Information technology has the potential to transform chronic disease management by directly connecting clients to caregivers and personalizing services in response to clients' unique needs and preferences (Coughlin et al., 2006). Technology-enabled care systems also offer the promise of strengthening an understaffed and under-resourced home healthcare industry (Coughlin et al., 2006).

Coughlin et al. (2006) identify a number of factors that must be in place before synergies between technology, chronic disease management and home healthcare can be realized. First, they recommend incorporating technology and chronic disease management into the standard education curriculum and practice for home healthcare providers. Second, public policy must provide incentives to developers of technology while guaranteeing that resulting innovations are available, affordable and acceptable to clients and their families, regardless of socioeconomic status. Third, practical research must be conducted to assess the effectiveness of new devices and technologies by large populations in the home and community care sector. Moreover, a study by Rogers et al. (2005) found that enhancing the practice of client-centredness in the context of self-management is likely to require a greater appreciation of bottom-up self-management concerns by professionals and changes to organizational infrastructures to allow for flexibility in the time and nature of client-provider consultations.

7.4 Telehealth

A new emphasis on cost containment and meeting client preferences has resulted in healthcare moving from a hospital-, clinic- and physician-centric realm to services being delivered in the home (Huvane, 2008). Technological advancements known as telehealth are facilitating the expansion of clinical practice from the office or hospital to the community (Moore & Wasson, 2006; Huvane, 2008). Telehealth is defined as the electronic provision of healthcare and information services for the direct benefit of individual clients and their families.



It includes healthcare provider-client and provider-provider interactions and the provision of education and information services designed to increase awareness of diagnoses, treatments and good health practices (Russo, 2001). Numerous studies show the potential of home telehealth to improve client-centred care, client outcomes and provider efficiencies.

A study by Lutz et al. (2009) demonstrated the feasibility of implementing a post-stroke home-telehealth program (specifically an in-home messaging device) for assessing a stroke client's physical function, depression, fear of falling, likelihood of falls and near falls, as well as their family caregiver's burden. Qualitative analyses revealed that study participants overwhelmingly thought home telehealth provided a 'safety net' and was a useful supplement to their post-stroke recovery, especially if it was combined with real-time face-to-face or phone contact with a care coordinator. They indicated the need for home telehealth programs that were easy to understand, provided stroke-related information and were designed specifically to meet their needs as they saw them (Lutz et al., 2009).

A study by Chumbler et al. (2005) examined the effectiveness of a U.S. Department of Veterans Affairs (VA) client-centred care coordination/home telehealth (CC/HT) program as an adjunct to treatment for veterans with diabetes. The CC/HT program consisted of a care coordinator (Registered Nurse or Advanced Registered Nurse Practitioner) who applied disease management principles throughout the care continuum, managed treatment and equipped the veteran with self-management skills to avert later, more costly interventions such as hospitalizations and to increase preventive services, such as needs-based primary care clinic visits. The CC/HT program improved the ability of older veterans with diabetes to receive appropriate, timely care, thereby improving the quality of care for them and making more efficient use of VA healthcare resources (Chumbler et al., 2005).

Another form of telehealth, known as telecare, is the term given to the remote monitoring of clients through information and communication technologies (Brown, 2003). The role of these telecare systems is to improve client outcomes and organizational efficiencies by providing health and community care professionals with remote client monitoring tools (Russo, 2001). These tools provide carers with the means to address the increasing demand for services, along with more client-focused care (Brown, 2003). Next generation telecare systems are capable of measuring changes in the individual's ability to live independently. Such systems are based on a network of sensors within the individual's home that monitor daily activities such as cooking, cleaning or answering the front door. The data retrieved from the sensors would then be processed to discover general trends in the ability of the individual to carry out these activities. Such a system might be capable of indicating the likelihood of an adverse incident such as a fall or injury.

Body-worn sensors, which are capable of monitoring vital signs such as heart rate or blood sugar level are another form of telecare. The sensors may also include a panic button that allows the individual to raise an alert if they find themselves in difficulty.



Body-worn sensors overcome the installation problems associated with a network of sensors around the home, but issues remain around the 'wearability' of such devices – they are intrusive and need power. Ultimately, the success of such systems is dependent upon user acceptance and remembering to wear the device (Brown, 2003).

A randomized trial by Jerant et al. (2003) compared three post-hospitalization nursing care models for reducing congestive heart failure (CHF) readmission charges during 180-days of follow-up. Subjects received in-person visits at baseline and 60 days, plus one of three care modalities in the interim: (a) video-based home telecare; (b) telephone calls; and (c) usual care. Results showed that CHF-related readmission charges were 80% lower in the telenursing groups compared to usual care and these groups also had significantly fewer CHF-related emergency visits. Home telecare visits were three times shorter than in-person visits and telephone visits were five times shorter than in-person visits, despite similar nursing care content in all three types of visits. Furthermore, no obvious decrements in client health status or satisfaction with care were observed (Jerant et al., 2003).

Other trends in telehealth that have the potential to significantly impact care delivery are video conferencing and wireless technology (Huvane, 2008; Russo, 2001). Video conferencing can be used to facilitate communications between clinicians and home-based clients. Video conferencing has the potential to improve the quality of the healthcare experience for clients; however, the biggest obstacle is reimbursement (Huvane, 2008). Wireless technologies also have the potential to improve communications between mobile workers and those based in hospitals or other care centers, as well as enabling community care to be delivered and documented in real time (Huvane, 2008). By utilizing wireless technology in the field, clinicians can transfer data at each visit and view any changes that have been made to client records. Furthermore, wireless systems provide navigation to clients' homes and facilities, track mileage, calculate mileage, track caregiver locations and manage assignments based on location proximity. Some solutions also come equipped with an emergency alert that can be deployed in case a clinician requires immediate assistance (Huvane, 2008).

A study by Jönsson and Willman (2008) used video consultation and web-based health information for clients receiving home healthcare for leg wounds. The results showed that nurses and clients felt positively about, and were interested in, using this form of communication. Clients felt positively about being able to see the staff caring for them via videophone, and seeing a face inspired a sense of security, which had a calming effect. The nurses felt that the web material was an educational resource for the client, next-of-kin, colleagues and coworkers. The nurses were unanimous in stating that with functioning technology in place, computer support both in real-time and for "store-and-forward," was helpful in their everyday work. The nurses also felt that their time at work was better utilized and that the virtual communication between clients and nurses constituted a humane complement in home healthcare (Jönsson & Willman, 2008).



Finally, mobile health (m-health) initiatives are those that use mobile communications such as mobile phones and personal digital assistants (PDAs) for health services and information. M-health has been described as a client-centred approach to care, as it consists of social networking, participation, collaboration and openness. Specifically, social networking is a potentially powerful tool to engage users, in that it provides social incentives to enter, update and manage personal information (Barton, 2010). An article by Barton (2010) highlights the potential of m-health interventions to promote behaviour change and monitor population health.

7.5 Barriers to the use and implementation of information systems (IS) and technology

Although the potential benefits of technology for the improvement of healthcare are well documented, technology itself and the way humans use IT may not overcome the many obstacles to the attainment of client-centred care (Moore & Wasson, 2006). Technology is a tool that will allow clients and clinicians more choices. However, numerous issues that act as barriers to the use of technology in healthcare have been identified including design problems, technology looking for an application rather than stemming out of actual need, equipment failures, problems with devices not being interchangeable, regulatory and licensure barriers, high costs of devices and connectivity, privacy, security and confidentiality and the substantial time needed to learn how to use the technology and gain an acceptable comfort level (Rahimi, Vimarlund & Timpka, 2009; Russo, 2001).

Rahimi, Vimarlund and Timpka (2009) used a qualitative meta-analysis to organize the knowledge gained in qualitative studies performed in association with the implementation of healthcare information systems (HIS) in the hospital and primary care sectors. The synthesis identified eleven important areas for the implementation of IS/IT, organized into three domains, which may be transferable to home and community care:

- 1. The long-term strategic domain: management involvement, motivation and rationales, surveillance of system effectiveness and information needs assessments;
- 2. The medium-term tactical domain: education and training support, the implementation process and methods, work routine and workflow integration and system integration;
- 3. The day-to-day operational domain: trust, user participation and involvement and technical system performance.

Importantly, the authors note that implementing healthcare information systems will not automatically increase the efficiency of a clinical organization. The system is a tool for establishing a process that can be used to continually improve clinical and administrative functions.



They recommend the following strategic, tactical and operational actions be taken into consideration when implementing IS/IT: management involvement, HIS integration in healthcare workflow, user involvement (transition period), establishing compatibility between software and hardware, education and training (Rahimi, Vimarlund & Timpka, 2009).

Walker and Carayon (2009) reviewed the current task-focused state of health IT and propose the need for increased attention to processes in health IT. Task focused care is centred on the provider or facility, while process-focused care is centred on the client. The authors suggest that to deliver better healthcare at a lower cost, health IT should be redesigned to support improved, client-centred care, and not the isolated tasks of physicians and clinicians.

7.6 Electronic health record (EHR)

EHRs have not been as readily adopted by medical practices and health systems, as their apparent utility might lead us to expect (Atienza et al., 2007). This is partially due to the fact that providers cannot choose the features of an EHR, but instead must buy a vendor package, ultimately getting some features that they need but others they do not, at a premium price (Kibbe, 2009). Kibbe (2009) believes that a shift from this vendor-centric approach, to one that is platform-centric and modular, would be more attractive to medical practices and result in better uptake of EHRs.

Bates and Bitton (2010) suggest that EHRs available today need further development in seven domains to improve their efficiency, quality and safety. These domains are: clinical decision support, registries, team care, care transitions, personal health records, telehealth technologies and measurement. Two domains of particular importance for the home and community care sector are care transitions and team care. Care transitions, such as from the hospital to home, are vulnerable times for clients. One study found that 12% of clients suffered an adverse drug event after being discharged (Forster et al., 2003). Comprehensive EHRs could help manage care transitions more effectively by facilitating processes such as client follow-up in the community and medication reconciliation (Bates & Bitton, 2010). A cornerstone of effective care in the community is collaboration amongst healthcare providers. EHRs must be improved to enable real-time communication and coordination among team members to promote this collaboration (Bates & Bitton, 2010). Furthermore, the application of EHR innovations should target client-centred goals, such as facilitating clients to be more involved in their care by creating shared after-visit care plans that evolve in real time (Bates & Bitton, 2010).



8. EVIDENCE-INFORMED IMPLEMENTATION STRATEGIES FOR CLIENT-CENTRED CARE

To integrate client-centred care into practice, a significant shift in the approach to care is required. There is an increasing evidence base which outlines the challenges of both behaviour change and integration of new research findings into practice within the clinical environment (Grimshaw et al., 2001). Recognition of the complexities of change has led to an understanding that, in order to facilitate and implement change, knowledge translation strategies should involve multiple approaches and interventions (McWilliam, Kothari, Kloseck, Ward-Griffin & Forbes, 2008a; McWilliam et al., 2008b) aimed at identifying and addressing context specific barriers and challenges (Grimshaw et al., 2001).

The complexities of trying to support and facilitate a change towards the delivery of client-centred care have been identified in a growing literature base, which includes evidence from discipline-specific analyses (e.g., nursing, medicine, occupational therapy), conducted in multiple environments (e.g., acute care, home and community sectors). These factors, in addition to the heterogeneity of definitions and outcomes measured for client-centred care, create challenges for the interpretation, application and generalizability of the findings. Despite these limitations, the lessons provided in the literature relating to implementation are extremely valuable to help inform future strategies within the home and community care environment. This section will review the literature regarding the barriers and implementation strategies for client-centred care at the following three levels: individual/point of care, team/organizational, and environmental/system. Importantly, there is a general consensus that the practice of client-centred care should be a shared responsibility between healthcare providers, organizations and the broader healthcare system (Brown et al., 2006; Cott, 2004; RNAO, 2006).

8.1 Individual/Point of care level

There is a significant amount of literature which examines the provision of client-centred care as an interaction between healthcare provider and client. This has resulted in a growing body of knowledge concerning both the implementation strategies and barriers encountered at this intersection.



8.1.1 Barriers to implementing client-centred care at the individual/point of care level

Healthcare provider barriers

A number of factors that may act as barriers to the conduct of client-centred care by the healthcare provider have been identified in the literature and are listed below. These findings have emerged from studies undertaken from a variety of discipline perspectives (including dietetics, occupational therapy, nursing and medicine) and have been included together in this analysis as it is reflective of the interdisciplinary teams present in the home and community environment.

Professional practice concerns

- Misalignment of goals A healthcare provider may bring specific goals to the interaction with the client (either identified personally or by the system within which they practice) which are not congruent to those of the client (Sumsion & Smyth, 2000; Wressle & Samuelsson, 2004).
- Education and experience A healthcare provider may find it difficult to work towards goals and provide services that significantly differ from those that their education/experience suggest may best address the client's needs (MacLellan & Berenbaum, 2007).
- Conflict between integration of best practices and client-centred care This would include
 uncertainty as to whether client-centred care practice is in contradiction with the use of best
 practices for care (e.g., resulting in potential risk to the client) (Bauman et al., 2003; Sidani,
 Epstein & Miranda, 2006; Litchfield & MacDougall, 2002; Morgan & Moffat, 2008; Schoot et al.,
 2006).
- Conflict in models of care Specifically when healthcare providers attempt to provide client-centred care (e.g., models of working and partnership) while practicing and/or trying to conform to the medical model of care (Brown et al., 2006; Sumsion & Lencucha, 2009; Sumsion & Smyth, 2000).
- Credibility A healthcare provider may fear loss of professional credibility and/or feel the need to assert themselves as expert to support their professional role (Litchfield & MacDougall, 2002; MacLellan & Berenbaum, 2007).
- Negotiation of roles and boundaries Challenges regarding the task of determining their role and relationship with the client when implementing care (Litchfield & MacDougall, 2002; Schoot et al., 2006; Silow-Carroll et al., 2006).



Personal characteristics

- Values and beliefs A healthcare provider's values and beliefs may prevent them from accepting
 the client's goals (e.g., clients may choose a treatment option that is not congruent with the
 provider's values/beliefs/opinions) (Chapman et al., 2003; Sumsion & Smyth, 2000; Wressle &
 Samuelsson, 2004).
- Motivation A lack of motivation to implement client-centred care and change practice may impede implementation (Gillespie et al., 2004; Wressle & Samuelsson, 2004).
- Resistance Not perceiving the need to aquire new skills in order to be able to provide client-centred care, particularly if this apporach was not included in the provider's original training (Gillespie et al., 2004; RNAO, 2006; Silow-Carroll et al., 2006; Wilkins et al., 2001).
- Power A healthcare provider being uncomfortable/unwilling to share power with clients (Gillespie et al., 2004; Litchfield & MacDougall, 2002; Sumsion & Smyth, 2000; Wilkins et al., 2001).

Structural impediments

- Lack of education/skills Healthcare providers may lack skills regarding how to 'be' client-centred or practice in this way (Wilkins et al., 2001; Wressle & Samuelsson, 2004).
- Time A lack of time may restrict the type of relationship that can be developed with a client and/or may impact upon the ability to meet a client's expectations (Chapman et al., 2003; Corring & Cook, 1999; Litchfield & MacDougall, 2002; MacLellan & Berenbaum, 2007; RNAO, 2006; Sumsion, 2004; Sumsion & Lencucha, 2009; Wilkins et al., 2001; Wressle & Samuelsson, 2004).
- Understanding There is a lack of a comprehensive, agreed upon definition of client-centred care and what this entails, which impedes implementation (Gillespie et al., 2004; MacLellan & Berenbaum, 2006).

Client barriers

As the client and healthcare providers are considered equals in client-centred care, the client's role, characteristics and attitudes have a significant impact upon the care provided. These may represent a barrier to client-centred practice in cases where the client elects not to, or is unable to, participate in care. A brief exploration of these factors is outlined below.

- Preference Clients may prefer a relationship of deference to the physician/clinician/provider as expert (Silow-Carroll et al., 2006; Sumsion, 2005; Wilkins et al., 2001).
- Internal resources and demographic characteristics Lack of decision making ability, age, education and socio-economic status can be challenging when establishing a shared understanding of health and care (Gillespie et al., 2004; Sumsion, 2004; Wilkins et al., 2001).



- Diagnosis Clients with acute/severe illness may not want to function as partners and those with significant cognitive impairment may not be able to provide informed consent (Silow-Carroll et al., 2006; Deber, 1994 and Hobson, 1996, cited in Sumsion, 2005; Wilkins et al., 2001).
- Culture Decision-making structures within certain cultures may impact upon a client's desire to participate as a partner in care (Gillespie et al., 2004; Silow-Carroll et al., 2006; Sumsion, 2004; Sumsion & Lencucha, 2009)
- Language barriers In order to engage collaboratively with a healthcare provider, the client must have the language skills and ability to facilitate participation (Gillespie et al., 2004; Silow-Carroll et al., 2006; Sumsion, 2004; Wilkins et al., 2001).

8.1.2 Implementation strategies for client-centred care at the individual/point of care level

In order for client-centred care to truly be realized, healthcare providers must first develop a comprehensive understanding of what is meant by the term (Sumsion, 2006; Wilkins et al., 2001). This can be a challenge given the absence of an accepted definition, which raises concern about "misinterpretation and inappropriate use" (Dieppe & Horne, 2002, cited in Gillespie et al., 2004, pg. 147). This lack of understanding was demonstrated in research conducted by Gillespie et al. (2004), who undertook a qualitative, exploratory study examining how client-centred care is understood by a range of stakeholders from health agencies, Royal Colleges, educational institutions and client/consumer organizations in the UK. Using theoretical sampling techniques, the researchers conducted 47 interviews with participants, all of whom play a role in translating the concept from theory into practice. The findings illustrated that the concept of client-centred care was 'complex and contested' (pg. 147). Furthermore, there was a considerable range in understanding and application of the concept, often dependent on the professional's role or discipline. This resulted in the development of discordant views of what constitutes client-centred care practice and a lack of symmetry between policy and clinical practice, leading to a lack of awareness regarding the breadth of possible clientcentred activities (e.g., from public involvement to individual interactions with clients). The authors emphasize the need for system-wide policy to integrate findings of academic client-centred care research in order to result in change at both the individual level and the broader system. The authors also note that without a common definition, change in practice is unlikely (Gillespie et al., 2004).

This finding is echoed in the work of by MacLellan and Berenbaum (2006; 2007) who explored how Canadian dieticians understood client-centred care through of the use of a two-round Delphi survey (n=48 for both rounds [2006]) and open-ended interviews (n=25 [2007]). Results indicated that participants generally believed that client-centred nutritional counselling referred to meeting clients' 'needs and wants'; however, there was not a consistent approach to the application of this in practice, and many felt the realities of their workplaces limited the extent to which they could practice client-centred care (MacLellan & Berenbaum, 2006, 2007).



Implementing client-centred care requires a great deal more than an understanding of the concept. It requires a significant change in the approach to care, including not only the specific care behaviours (e.g., incorporation of new techniques to facilitate client-centred care such as shared decision making, partnership, etc.), but also the attitudes underlying the healthcare providers' philosophy of care, including a willingness to 'share' power and change traditional dynamics within the client/provider relationship (Brown et al., 2006; Corring & Cook, 1999; McWilliam, 2009; Sumsion & Law, 2006). Some argue that a decision to practice in this manner is actually a moral choice (Rochon & Baptiste, 1998, cited in Wressle & Samuelsson, 2004).

The literature is strongly supportive of the need to educate healthcare providers in client-centred care provision as a way to implement changes in practice (RNAO, 2002; Silow-Carroll et al., 2006; Sumsion & Smyth, 2000; Wilkins et al., 2001; Wressle & Samuelsson, 2004). This education may include the use of case studies (Sumsion & Smyth, 2000), sharing ideas/solutions between staff members and/or the use of mentoring and critical reflection (Wilkins et al., 2001). The importance of educating all staff helping to provide a client with care has been highlighted, as evidence suggests that, although possible, it is more challenging for a lone healthcare provider or discipline to implement a shift to client-centred care independently (Restall & Ripat, 2008; Sumsion & Lencucha, 2009; Sumsion & Smyth, 2000; Wilkins et al., 2001).

Sumsion and Law (2006) identified a list of practice questions for therapists to ask themselves, when implementing client-centred care, to assist them in reviewing their approaches. These questions, outlined in Table 3, facilitate reflection on the key concepts identified by the authors in a detailed review of the literature: power, listening and communicating, partnership, choice and hope.



Table 3 – Practice questions for healthcare providers

Component	Practice Questions			
Power	Do I use language that is easy for clients to understand? Do I use language that conveys my goal to work in partnership with the client?			
	Do I advocate for systems and policies to be changed so clients can assume power for their program?			
	Do I provide quality information at a level my clients can truly understand?			
	What are the most important pieces of information my clients need?			
	What is the best format in which to provide this information?			
	Do I check that they have understood the information I provided?			
	Do I tailor information to the specific needs of the clients and their family?			
	Are my clients able to apply the information I have provided?			
Listening and	Do I truly listen to what my clients are saying and not just to their words?			
Communicating	Do I leave enough time so that clients are able to tell me about their occupational performance issues?			
	Am I able to develop an understanding of a person's values after talking to them?			
	Do I let an interview unfold naturally, rather than structuring each question that I ask of the client?			
	Do I share my perceptions of what the client said with them to confirm if I am interpreting their information correctly?			
	Do I take the time to listen and truly hear their stories?			
	Do I facilitate a process of ensuring my client's voice is heard?			
	Do I work in partnership with my clients to obtain the required information?			
	What does the concept of partnership mean to me?			
Partnership	Do I truly work in partnership with my clients?			
	What contribution do we both bring to this partnership?			
	What is the connection between a partnership and power?			
	Do I enable choice through the occupational therapy process?			
Choice	Am I able to facilitate small choices if larger ones are not possible for the client to make?			
	Do I apply my occupational analysis skills to create opportunities for choice?			
	Am I prepared to facilitate the process by empowering the client?			
	Do I understand and accept the importance of hope for my clients?			
Нопо	Do I provide opportunities for clients to express their hope to me?			
Hope	Do differences in opinion between myself and the client represent different values rather than different goals?			
	How can I incorporate their hope into the intervention plans?			

^{*}From Sumsion & Law, 2006, pg. 159. Reprinted with permission from CAOT Publications ACE.



In 2003, Restall, Ripat and Stern introduced the Client-Centred Strategies Framework for Occupational Therapists, which can be used by a variety of practitioners from novice to experts to address and overcome barriers to client-centred practice. The framework has grouped suggested actions into five categories that provide occupational therapists with suggested activities, which they can consider, tailor and administer as appropriate to their practice. The five categories extend from the point of care (healthcare provider and client interaction) to system-wide strategies. Definitions of the categories and examples of suggested actions which are included in the framework are summarized in Table 4 below.

Table 4: Examples of the Categories identified in the Client-Centred Strategies Framework

Category	Summary	Examples of strategies		
Personal reflection	Explore and consider their knowledge, values and beliefs as it relates to their practice and implementation of client-centred care. Through reflection, situations of conflict or challenge to the implementation of client-centred care within the clinical environment may be negotiated and evaluation of one's practice can be considered.	 Reflecting on personal values and beliefs to learn more about yourself. Keeping a professional reflective journal to examine clinical practice. 		
Client-centred process	Involves the active and considered implementation of client-centred strategies including the use of available tools and resources and consideration of the best approaches given the particular clinical setting.	 Use of tools and evaluation processes for client-centred care. Educating clients about client-centred care. 		
Practice settings	Refers to the creation of a practice environment which supports the provision of client-centred care. This goes beyond the level of client and healthcare provider interaction to consider the broader factors influencing care.	 Revision of mission statement/job descriptions/ tools and policies to reflect a client-centred care philosophy. 		
Community organizing	Community-organizing activities can be grassroots or professionally driven and are activities or strategies which seek to empower communities to support and advocate for client-centred care practices.	 Establishing partnerships to build healthier communities. Conducting needs and strengths assessments. 		
Coalition advocacy and political action	Coalition and political advocacy strategies seek to bring together groups of people and/or professionals to advocate for larger systems change.	 Advocating for funding models which give clients control over how services are purchased and used. 		

^{*}Adapted from Restall, Ripat & Stern, 2003



8.2 Organizational level

The importance of the environment and culture of an organization has a significant influence upon the practice of client-centred care and the manner in which healthcare providers integrate it into their practice (Cott, 2004; RNAO, 2002). A healthcare provider attempting to change their approach to care will be limited in terms of what they can achieve without the broader system and structural support from the organization (RNAO, 2002). Cott states, that it is "unrealistic to expect health care professionals to practice in a client-centred manner if they are working in a system or organization that does not provide them with the resources that they need or that places demands on them that impede their abilities to be client-centred" (Cott, 2004, pg. 1420).

This is supported by others who argue that organizational values must be considered when providing client-centred care, as these must be balanced with the espoused values of client-centred care (McCormack, 2004; Wilkins et al., 2001). Essentially, the ability to be 'client-centred' is directly impacted by the culture, mission, models of care delivery and administrative structures of an organization (Cott, 2004; RNAO, 2002; McCormack, 2004).

8.2.1 Barriers to the Implementation of client-centred care at the organizational level

Despite the importance and value of the organization in the implementation of client-centred care, a number of barriers exist in the reality of day-to-day practice.

Lack of organizational support

- A commitment to a widespread change of the care delivery culture is required for integration of
 the client-centred care approach (Litchfield & MacDougall, 2002; RNAO, 2002). Evidence shows
 that barriers to implementation exist if only one professional group or team is targeted or if
 healthcare providers attempt to make this change independently without systemic support
 (Cott, 2004; MacLellan & Berenbaum, 2007; Wilkins et al., 2001; Nolan et al., 2004).
- Perceived or actual conflict between organizational support for evidenced-based practice and commitment to client-centred care (Litchfield & MacDougall, 2002).

Environmental barriers

Culture – Within the clinical practice environment, issues such as limited resources (e.g., funding, staffing) and low staff morale may impede the ability of healthcare providers to implement a change to their care (Gillespie et al., 2004; RNAO, 2006). There are data to support the link between healthcare provider and client satisfaction (Rave et al., 2003, cited in Shaller, 2007). For client-centred care to be realized, healthcare providers must be awarded the same respect and care by their employer as they are expected to provide their clients (Shaller, 2007; Nolan et al., 2004).



- Education There is a need to support the implementation of client-centred care through
 activities such as staff education. Although there are costs associated with education, evidence
 suggests that it provides healthcare workers with the necessary knowledge and skills to change
 practice and allows them time to implement changes in their daily work (RNAO, 2006; SilowCarroll et al., 2006; Wilkins et al., 2001).
- Conflict between policy and philosophy Organizational structures/policies may exist which are
 in conflict with a client-centred care philosophy. This may take the form of excessive
 assessment requirements or limitations regarding the time or the nature of an interaction which
 can occur between a healthcare provider and client. Such factors impede the provision of
 client-centred care, as the existing system may not allow for a change (RNAO, 2006; SilowCarroll et al., 2006; Sumsion & Lencucha, 2009).

8.2.2 Implementation strategies for client-centred care at the organizational level

Many of the barriers identified above may be addressed through implementation of the strategies outlined in this section. The role of the broader organization in supporting a change to practice is essential and was highlighted by the RNAO Best Practice Guideline (BPG): "Client Centred Care" supplement following the initial pilot implementation of the guidelines in five organizations. This guide suggests that "successful client-centred care not only requires nurses to embrace the values and beliefs of client centred care but they need to do so in conjunction with the other professional team members and with the organizational support of appropriate policies and procedures" (RNAO, 2006, pg. 5). The RNAO (2006) recommends that nursing best practice guidelines can be successfully implemented only in environments where resources, organizational and administrative support and facilitation are present. Specifically, they suggest the development of an implementation plan, supported by funding and by senior leadership, which incorporates ongoing opportunities for discussion and education to reinforce learning and engaging in reflective practice (personal and organizational).

In an effort to achieve more rapid and widespread uptake of client-centred care at the organizational level, Shaller (2007) completed a report commissioned by The Picker Foundation, to identify the requirements which would help to facilitate change. A literature review was conducted and followed by interviews with key experts in both the design and implementation of client-centred care strategies and with leaders of organizations who have demonstrated 'excellence' in the area. This research identified a number of organizational strategies critical to the uptake of client-centred care. The results of this work are used below as a framework to organize implementation strategies or recommendations from the literature reviewed.



- Leadership The role of senior leadership in supporting and facilitating organizational change towards a client-centred model was cited by many of the experts interviewed by Shaller as the most important strategy to facilitate change. Leaders within an organization have a role in supporting the cause, contributing to a required change in culture and assisting a sustained change in practice (McWilliam et al., 2003; Nolan et al., 2004; RNAO, 2002; Silow-Carroll et al., 2006; Wilkins et al., 2001; Wressle & Samuelsson, 2004).
- A clearly communicated strategic vision Integrating client-centred care into the mission and vision of an organization aligns the client-centred approach to care with the daily operation and processes within an organization (McWilliam et al., 2003; RNAO, 2006; Shaller, 2007).
- Involvement of clients and families Engagement of clients and family members in client-centred care, not only at the point of care in terms of shared decision making and partnership, but also at the organizational level helps to integrate client perspectives in all areas of the organization (Corring & Cook, 1999; Shaller, 2007; Silow-Carroll et al., 2006; Wilkins et al., 2001).
- **Supportive work environment** The importance of the well-being and satisfaction of the healthcare workforce to their ability to provide client-centred care is supported by literature citing the alignment between client and healthcare provider levels of satisfaction (Nolan et al., 2004; Rave et al., 2003, cited in Shaller, 2007). A holistic, supportive approach for staff which included *"hiring, training, evaluating, compensating and supporting"* a client-centred workforce (Shaller, 2007, pg. 11) was supported by the experts interviewed.
- Systematic measurement and feedback Listening to feedback from clients in order to learn about the services delivered from the client perspective and to identify opportunities to improve their experience (Shaller, 2007; Silow-Carroll et al., 2006).
- Quality of the built environment The institutional environment and the design of the environment itself has been shown to impact the experience of the client; therefore the quality of the environment should be a key consideration (Shaller, 2007).
- Supportive technology Health information technology (ranging from basic email communication to electronic health records) can facilitate communication with healthcare providers and access to relevant information and decision support tools (Shaller, 2007; Silow-Carroll et al., 2006; Walters, Barnard & Paris, 2006; O'Connor et al., 2009).

Furthermore, Shaller (2007) recommends four practical ways that organizations can assist in implementation of client-centred care (pg. 18-19):

Leadership development and training:

 A strategy encompassing education and training about client-centred care for all levels of leadership was recognized as essential due to the important role of the leadership teams in supporting the shift to client-centred care.



Internal rewards and incentives:

• The experts participating in the study identified the need to identify strategies to reduce the turnover of these leadership teams. Strategies identified included the use of compensation and incentives which are linked to the client experience.

Training in quality improvement:

• The importance of the entire healthcare team working collaboratively to systematically apply quality improvement processes to improve client care experiences.

Practical tools derived from evidence-based practice:

• As the evidence base supporting client-centred practice continues to expand, access to knowledge and resources both at the point of care and at the management level will assist in the implementation of effective, evidence-based strategies.

8.3 System level

This review of the literature has identified numerous organizations across Canada which are directly and indirectly supporting the shift to client-centred care. There are common challenges that these organizations and groups face in implementing client-centred care, which are related to the healthcare system as a whole (Glover, personal communication, 2010). There is, however, the potential for synergies that exist between existing programs, services and professional practices to be leveraged to help enact changes in policy, practice and organizational structures in order to advance client-centred care in the home and community sector.

8.3.1 Barriers to the implementation of client-centred care at the systems level

In order for a paradigm shift to occur within the broader Canadian healthcare system, there is the need to address the system-wide barriers which are preventing change from proceeding. Key structural barriers that have been identified in the literature include: funding, system burden, the lack of supporting technology and a lack of systems integration.

Funding

The majority of existing funding arrangements across Canada for hospitals and community services offer little financial incentive for changes to practice and/or improved coordination of care. Altering this system to a structure that awards funding in alignment with performance and achievement of service delivery targets may support a fundamental shift in the system towards a new way of practicing (Ball, 2010; Ontario Medical Association, 2010). This approach to funding is being utilized in a number of countries including Australia, the United Kingdom, Norway, New Zealand and Germany (British Columbia Ministry of Health Services, 2010).



The province of British Columbia announced a shift to this method of 'client-focused funding' in April 2010, following the successful completion of a range of pilot projects that demonstrated increased coordination of care, decreased costs and decreased waiting times. Currently, this approach is being implemented only in the acute care sector; however, consideration is being given to include the provision of incentives for health authorities to better manage frailty, chronic disease and mental illness through community care, rather than in a hospital or residential-care setting (British Columbia Ministry of Health Services, 2010).

System burden

The increasing demands upon the Canadian healthcare system are broadly acknowledged and the prediction of future challenges is informing healthcare policy. Currently, the increasing demands have not necessarily been met with an increase in the supply or availability of service, creating bottlenecks in the healthcare system, which may negatively impact the client experience. Examples include delays in securing long-term care placements, lack of integration between hospitals and the community and demand outstripping supply of palliative care, chronic disease management and other community-based programs designed to help people stay in their homes (Ontario Medical Association, 2010).

Absence of supporting technology

At the current time, there is a lack of available, system-wide technology to support healthcare provision within Canada. As discussed previously, technology has the potential to bring about significant change and improvement to healthcare delivery, both within the home and community sector and across the entire healthcare system through improved coordination and communication, as well as reduced duplication of effort and expense (e.g., in the conduct of multiple diagnostic tests, client assessments, etc.) (Ontario Medical Association, 2010).

Lack of system integration

Currently, the Canadian healthcare system can be largely described as an assortment of separate and disparate systems, both across Provinces and Territories and within the systems themselves. This disparity creates challenges when trying to implement change across the country (Canadian Medical Association, 2010; Ontario Medical Association, 2010). Furthermore, the lack of integration between healthcare sectors within the broader system has resulted in poor client experiences (Ball, 2010).



8.3.2 Implementation Strategies for client-centred care at the systems level

Despite the extensive work of individual organizations, provincial and territorial governments and individual practitioners, true system-wide change has yet to occur. Several authors have investigated what would be required to realize change at this level. In the aforementioned report by Shaller (2007), which examined implementation strategies to increase uptake of a client-centred approach, the author recommends the following strategies as methods which can be employed to achieve system-wide support for the uptake of client-centred practice:

Public education and client engagement

• Educating the public about client-centred care and the tools and resources available to assist them to participate in their healthcare will help to complement the work of organizations implementing a client-centred approach. In addition, the involvement of clients at different levels within an organization helps to exert pressure to achieve and sustain client-centred changes in practice.

Public reporting of standardized measures

• Measurement of outcomes and progress is important for organizations and systems to understand their performance and how this can be improved. Public reporting of these figures can assist in holding organizations accountable for their performance and stimulating change.

Accreditation and certification requirements

• Inclusion of client-centred care processes into the accreditation and certification requirements of healthcare organizations and healthcare providers provides a significant motivation for changing practice.

These recommendations are aligned with those proposed by healthcare consultant, Steven Lewis (2009), who prepared a series of discussion papers at the request of the Saskatchewan government regarding client-centred care within the province. In the paper titled, "Making Patient Centered Care Real: The Road to Implementation. A Discussion Paper for the Saskatchewan Ministry of Health," the author provides the following recommendations for implementing patient-centred care and helping to achieve change at the broader systems level (Lewis, 2009, pg. 5-7):

- 1. Draft a patients' charter of rights and expectations that define core elements of patient-centred care;
- 2. Mandate a review of the educational measures needed to support patient-centred care;
- 3. Encourage regulatory bodies, accreditation agencies and professional associations to incorporate patient-centred care into their core expectations, codes of ethics, etc.;
- 4. Develop patient-centred care continuing education programs for managers, practitioners, case coordinators, volunteers, and the public, using multi-faceted techniques such as simulation, to expand capacity and spread the concept;



- 5. Develop organization and practice-specific PCC indicators and certification programs that would be important and visible signs of commitment to the concept and create healthy competition. Imagine a prominent "this is a patient-centered care organization" sign at the entrance to a doctors' office or hospital;
- 6. Develop a sustained communication strategy for promoting patient-centred care;
- 7. Create a network of paid and volunteer patient navigators trained in patient-centered care concepts and empowered to advocate, educate, and coordinate;
- 8. Set up a multi-stakeholder PCC Commission, led by and with majority public representation.

Additional suggestions include (Lewis, 2009, pg. 7):

- 1. Send motivated clinicians to PCC environments where they can see it in action and acquire new ways of doing things;
- 2. Design a PCC collaborative that includes patients;
- 3. Conduct focus groups, make videos, hold webcasts where people can discuss PCC and learn to listen to their customers;
- 4. Create checklists and reminders for both providers and patients;
- 5. Bring home care and long term residential care into the centre of the conversation these are areas with unsung PCC achievements;
- 6. Create awards for achievements in PCC based on empirical evidence.

8.4 The home and community sector

All of the implementation strategies and identified barriers discussed thus far are relevant to the provision of client-centred care within the home and community sector; however, this environment is predisposed to additional challenges, given that the delivery of care is outside the walls of a discrete environment.

8.4.1 Barriers to the implementation of client-centred care in the home and community sector

The complexity of client-centred care within the home and community environment was highlighted by the work of McWilliam et al. (2004). In a study which supported the implementation of an empowering (client-centred) model of service delivery, the researchers reported a myriad of challenges in the implementation of the intervention including: government-mandated changes to case management (including more centralized management and resource control), the introduction of retraining demands and requirements, and turnover of key staff members (McWilliam et al. 2004). These factors had a negative impact on the uptake of the intervention and consequently impacted upon the study findings.



Barriers that are specific to implementation of client-centred care within the home care environment were also examined through textual analysis of interviews from occupational therapists collected in three qualitative studies (Wilkins et al., 2001). These studies examined the implementation of client-centred care practice in three different clinical settings in Ontario, Canada: family-centred service in children's rehabilitation centres; community-based home care; and institutional/facility-based care for older adults. While several of the barriers identified are common to other sectors of the healthcare system and are similar to those outlined above, the barriers particularly relevant to the home and community environment were process issues, financial pressures, time and resources, communication challenges and personal barriers. These are explored in greater detail below and are supplemented with other evidence also reported in the literature.

Process issues

Services in the home and community sector are offered within a multidisciplinary context, by a range of regulated and unregulated healthcare professionals. Healthcare providers are influenced by policies and administrative structures (Wilkins et al., 2001). Brown et al. (2006) report that factors such as "centralized allocation and control of service delivery" impeded client-centred care provision (pg. 164). These findings were supported by Bosman et al. (2008), who found that when decisions rested outside of the care dyad (e.g., with the organization), the direction of care could be at odds with client preferences, particularly in relation to timing of service and continuity of care provider.

Financial pressures

The provision of care in the community is particularly vulnerable to financial pressures, especially in areas where such care is managed in a competitive bidding environment and/or there are ongoing strategies to reduce costs (e.g., visit length, number of visits, etc.) (Brown et al., 2006; Oudshoorn et al., 2007; Schoot et al., 2006; Sumsion & Lencucha, 2009).

Time and resources

Within the context of home care, there are significant constraints and expectations placed on the healthcare providers by the organization to resolve specific, health-related issues within a designated time period. This is a consequence of the design of the system, but has direct impacts on how organizations manage their structures and, ultimately, on the time available for providers to enact client-centred care (Brown et al., 2006; Gantert et al., 2008; Schoot et al., 2006; Sumsion & Lencucha, 2009; Wilkins et al., 2001). The practice of client-centred care may therefore be impeded by limited consultation or visit times (Wilkins et al., 2001), lack of relationship development (Gantert et al., 2008) and/or a limited scope of service during their interactions (Wilkins et al., 2001).



Communication challenges

Another challenge within the home and community care sector is that often healthcare providers are working in remote and disparate locations, making it especially difficult to bridge the gaps of communication between providers, administration staff, management and clients (Gantert & McWilliam, 2004). Communicating a client's wishes, experiences and/or the plan of care within this context can be difficult and therefore opportunities for client-centred practice may be lost.

Personal barriers

Further barriers to the application of client-centred care in the home and community environment stem from individual concerns of the healthcare providers who are being asked to enact change. This may include concerns about remuneration, workload and working conditions (Brown et al., 2006).

8.4.2 Implementation strategies for client-centred care in the home and community sector

Within Canada, McWilliam et al. (2003) report on the numerous strategies utilized in the implementation of the flexible, client-driven care model (Section 5.2) in the home care setting within southwestern Ontario. This model emphasizes relationship building and an empowering partnership-approach, which was implemented not only at the point of care but also at the organizational level through partnerships between home care service providers and one Community Care Access Centre (an organization responsible for the coordination and monitoring of public home care services). In this context, the experience of mutual knowledge, connecting and caring and the building of a mutual trust and understanding resulted in the emergence of a partnership which refined the service delivery model.

Examples of the strategies implemented to support this include (McWilliam et al., 2003):

- The integration of the model of flexible, client-driven care into the core values and activities of
 each organization engaged in enacting this model of care. Examples of this integration
 included expression of the model in the values, vision and mission statements, as well as
 policies, procedures and daily work transactions;
- Education to support learning and change for all stakeholders (including a workshop and ongoing opportunities for education for a critical mass of staff);
- Implementation of a "train the trainer" approach to support practice change;
- A focus on the development of empowering care partnerships at every level;
- Encouragement of reflective practice, self-evaluation and exchanges of information about experience;
- A communication plan to engage providers and the public which incorporated clear messaging, fact sheets, newsletters, and information packages;



- Formal memorandum of understanding between all partnering organizations which reorganized employees into 'neighbourhood teams';
- Use of mentors to help facilitate change;
- Creation of a leadership committee, known as the Inter-Agency Leadership Partnership (IALP) to provide role modeling by developing, supporting and sustaining partnerships;
- The rearranging of care to align with the philosophy of the model (e.g., use of an in-home client functional status record which includes a focus on client strengths and health as a resource for everyday living, in addition to medical problems and functional limitations);
- Revisions to the protocol for care management to an approach in which the client's preferences set the direction for care;
- Incorporation of assessment of progress toward care partnerships into the performance appraisal of staff members;
- Development of a shared continuous quality improvement (CQI) infrastructure to continue to develop and benefit from learning efforts as a collective.

Following work by Schoot et al. (2005a,b), Schoot et al. (2006) examined nurses' perspectives of delivering client-centered care in the home environment. Data were collected through participatory interviews conducted with 10 home care nurses providing care for 45 clients. Results indicated that nurses experienced conflict between their roles as a professional nurse, employee, individual, and their work as a 'responsive professional' wanting to address the needs and perspectives of their clients. Client-centred care required effectively balancing between competing responsibilities, client preferences/goals and professional standards. Four strategies implemented by nurses to manage these competing responsibilities were identified: pleasing (acting in accordance with the client's demands), dialoguing (sharing responsibility for care with the client), directing (the nurse making decisions on behalf of the client, putting professional values ahead of the client's), and detaching (orienting to the task and detaching from client needs and preferences). In order to address these conflicts, the following recommendations were made to assist in the balance between competing responsibilities (Schoot et al., 2006, pg. 251):



- **Critical ethical reflection** In collaboration with colleagues and managers, critical ethical reflection by care providers may facilitate awareness of roles, responsibilities and consequences of actions in relation to client care;
- **Development of the care relationship** Knowing the client, their preferences/goals and the context of the client situation is recommended in order to develop a relationship with a client, characterized by mutual respect and involvement;
- Being a critical partner in dialogue Using critical, creative and flexible strategies to balance between the competing responsibilities of the client's preferences/goals and those of the nurse is an essential element in the delivery of client-centred care. This can be facilitated through the use of communication skills that specifically utilize dialogue and negotiation strategies. Specifically, those nurses who utilize the strategy of pleasing may benefit from the development of self-assertiveness in order to contribute to responsibility taking;
- **Providing conditions for the care relationship** Policy makers are encouraged to provide conditions that facilitate the development and sustainability of a care relationship, such as sufficient time and decentralized planning;
- **Improvement of professional autonomy** Policy makers are recommended to improve professional autonomy in general;
- **Further research** Further research is needed in areas such as the impact of competence development in nurses and the effects of a supportive organization.



9. MEASURING CLIENT-CENTRED CARE

It is important to evaluate the presence and perceptions of client-centred care, as well as its impact in order to support the development of approaches, policies and frameworks to support its use (Edvardsson et al., 2008; Edvardsson & Innes, 2010; Robinson et al., 2008; Sepucha, Fowler Jr, & Mulley Jr, 2004). This section will first outline some considerations in the measurement of client-centred care outcomes, followed by a review of the different methods of assessing client-centred care, including those specific to home and community care.

9.1 Considerations for measuring client-centred care outcomes

In an article examining the theoretical and practical issues involved in the measurement of outcomes of patient-centred communication (PCC) in client-physician consultations, Epstein et al. (2005) provided a series of recommendations regarding the development of measures. Despite the fact that their work did not specifically address the measurement of client-centred care in the home and community environment, their recommendations are relevant to the identification of measures in this sector and could be adapted accordingly. A summary of these recommendations is provided below (pg. 1524):

- 1. Clear, theory-based operational definitions of PCC and its components should be used in PCC research;
- 2. There should be clarity about what is being measured. Measures should be named according to the construct they measure;
- 3. Measures should account for the communication behaviours of each individual in the encounter, as well as interactions among them;
- 4. Measures should account for context:
- 5. There is a need to validate instruments that purportedly assess communication behaviours that constitute PCC;
- 6. Caution should be used in interpreting client ratings of their physicians; such measures are subject to client effects (e.g., personality) and may conflate other parts of the healthcare experience with the encounter with the physician;
- 7. Although rare, longitudinal studies of PCC would illuminate the development of patient-centred behaviours over time;
- 8. Links between measures of PCC and distal outcomes should be theoretically grounded and include examination of pathways and mediators;
- 9. Researchers should work towards adequate ways of dealing with the complexity of the construct of PCC.



9.2 Methods of measuring client-centred care

The measurement of client-centred care is complex, as it requires careful identification of what, specifically, is to be measured (Epstein et al., 2005) - the subjective experience of client-centred care or the objective measurement of its presence.

The lack of a standard definition of client-centred care and its components has resulted in diverse interpretations of what is meant by the term and different approaches to implementation, outlined previously in this review (Robinson et al., 2008). There is no agreed upon "gold standard" tool for the measurement or reporting of client-centred practice (Lewin et al., 2001, cited in de Witte et al., 2006; Edvardsson & Innes, 2010). However, the literature reflects a genuine interest in assessing the presence or perception of care, as well as the impact of that care on a client's health. A myriad of approaches to gathering this information have been reported in the literature, including the measurement of:

- The client's perceptions of client-centred care (i.e., if the client believed the care to be client-centred);
- The healthcare provider's perspective or opinion regarding their provision of client-centred care;
- The presence of specific behaviours which have been identified as 'client-centred' (e.g., the use of specific communication techniques);
- The use of proxy measures to assess the impact and/or presence of client-centred care and interventions.

While traditional, quantitative measures of effectiveness will continue to be an important method for assessing the impact of client-centred care, evaluation should also include the measurement of outcomes identified as important by the clients themselves (Epstein et al., 2005). Including client-identified outcomes would truly be more reflective of a client-centred philosophy of care. Consideration of such outcomes illustrates the challenge of renegotiating practice from a provider-centred model to one which is truly embracing of the client and their perspective (Cott, 2004; Cott et al., 2006).

9.2.1 Subjective measurement of client-centred care

Client perceptions

It can be argued that the client's perception of the presence of client-centred care (Robinson et al., 2008) and its overall impact on their satisfaction with service are the most important elements to be evaluated. A study by Stewart et al., (2000) demonstrated that a client's perception of practice being client-centred was correlated with an improvement in health outcomes.



Client questionnaires are a commonly used method to assess client perceptions of their experience of care and/or their satisfaction with the healthcare interaction (Robinson et al., 2008). This raises the methodological question of whether client satisfaction with services equates to client-centred care. A challenge with this type of methodology is the way in which the language and terminology used may be understood by the client and, consequently, how this may limit the interpretation of responses. Robinson et al. (2008) provide the following example: "A patient may respond that the provider listens carefully but that does not identify what constitutes listening carefully" (pg. 602).

A proposed alternative is the measurement of client-centred care using an approach similar to the standardized and widely-accepted measurement of a client's pain which uses a simple Numeric Rating Scale to measure the client's perceptions of the experience. This simple tool could elicit the client's impression of the experience of client-centredness and could be investigated further to determine whether there are correlations between ratings on this tool and subsequent adherence to therapy (Robinson et al., 2008).

A number of tools have been developed to specifically measure clients' perception of client-centred care in the home and community sector and are explored in detail below.

Healthcare provider perceptions

Self-report methodology can be a valuable way to assess the presence of client-centred care from the provider's perspective. The RNAO Nursing Best Practice Guidelines: Client Centred Care (2002) recommends the following process indicators for nurses to reflect upon to evaluate and monitor their client-centred care practice (pg. 32):

- Listening (recognition of importance) to the client;
- Techniques (e.g., use of open-ended questions);
- Documentation (recording the client's perception/understanding, rather than the nurse's judgment);
- Client's perceived needs for care;
- Client's goals for care;
- Documentation of client's personal goals for care;
- Client's concerns/choices communicated with other members of the healthcare team;
- Discharge teaching guided by the client's goals for managing their care at home.

This type of self-reporting can be completed independently by the care provider for the purposes of reflection or as part of a more formal evaluation. Formal reporting, although relatively easy to administer on a large scale, has a number of limitations. The potential exists for reliability to be skewed due to social desirability bias resulting from perceived pressures or feelings of obligation to adopt a more client-centred approach to clinical practice (Mead & Bower, 2000a). There is also a lack of evidence to support a link between self-reported attitudes of healthcare providers and actual clinical behaviour (Mead & Bower, 2000a).



9.2.2 Objective measurement of client-centred care

A multitude of approaches have been used to objectively measure the presence of client-centred care, including direct measurement techniques (audio-recordings, observation) and the use of proxy measures (Robinson et al., 2008). However, as discussed previously, client-centred care is not a singular intervention, rather it is a concept comprised of several different but inter-related components. When measuring this multifaceted construct, careful consideration must be given as to what is being measured (Epstein et al., 2005).

Direct measurement

Direct measurement has been used to both document and determine the presence of client-centred care and may involve interactional analyses, coding systems, checklists and/or rating scales to identify whether a specific behaviour has been demonstrated (Epstein et al., 2005; Mead & Bower, 2000a,b). This method of measurement has been reported by a number of researchers in the investigation of patient-centred care and communication, particularly in the context of a medical consultation (Epstein et al., 2005; Mead & Bower, 2000a,b; Stewart et al., 2000). Limitations of this method include the challenges of consenting clients and healthcare providers to participate, the possibility that their interactions may be biased by the fact that they are being observed (Epstein et al., 2005), and issues relating to the reliability of ratings by observers (Mead & Bower, 2000a,b). In addition, the use of a standardized, quantitative tool for the measurement of client-centredness has other potential limitations in that it may miss important aspects of the interaction that are related to its practice, and/or the observation may capture only the patient's vocalized needs and not those which remain unspoken (Epstein et al., 2005).

Proxy measures

Some studies have used proxy outcome measures as indications of the presence of client-centred practice and to evaluate its effectiveness. For example, Edvardsson and Innes (2010) report the following proxy descriptors of person-centred practice have been used in the dementia literature: the prevalence of behavioural and psychological symptoms of dementia, use of neuroleptic medications and quality of life (pg. 835). If an 'improvement' in these measures is identified, this is interpreted as an indication of a higher degree of person-centredness (Edvardsson & Innes, 2010).

Other traditional "hard" measures of care have been used to determine the impact of client-centred care, including lipid levels, body mass index (BMI), haemoglobin A1c (HgbA1c) levels, and blood pressure(Robinson et al., 2008). There is a risk, however, that these measures may not be appropriate indicators, may be poorly designed and lack reliability and consistency due to a variety of possible confounding variables (Howie et al., 2004, and Franks et al., 2005, cited in Robinson et al., 2008). Wasson and Baker (2009) argue that the desire to rely on these measures, despite the possible methodological limitations or challenges which may result from their application, may be related to the traditional belief that bio-clinical data or 'hard' measures are more valuable than 'soft' or 'subjective' measures which may provide different meaning.



9.2.3 Measuring e-health and client-centred care

Specific consideration regarding the measurement of e-health-enabled client-centred care is warranted as research and evaluation methods have not kept pace with the rapid advancement of health information and communication technologies (Atienza et al., 2007). Adopting sound research methods is essential for designing and evaluating the effectiveness of e-health programs (Ahern, 2007; Atienza et al., 2010). In addition, the complexity of integrating technology and client-centred care research often requires an interdisciplinary approach, making the use of theory and sound methodological designs critical (Kuziemsky et al., 2009). Hesse and Shneiderman (2007) propose that potential errors in healthcare can be avoided by incorporating users' perspectives into e-health research and intervention design. They suggest that the designs of interventions and tools be guided by clients' and physicians' needs rather than by a priori models of need.

Finally, practical issues such as work flow must be must be considered when integrating health information technology and research designs into the clinical setting (Atienza et al., 2010). According to Atienza et al. (2010), "if widespread adoption, dissemination, and extended use of technologic health interventions are to occur, researchers must examine not only how technology-based health programs affect individuals, but also how individuals (and organizations) interact with technology and each other" (pg. 86).

9.3 Tools used to measure client-centred care in the home and community sector

A number of tools have been developed to measure client-centred care that would be suitable for administration in a variety of settings (e.g., long-term care homes, acute care, etc.) (Edvardsson & Innes, 2010). Table 5 summarizes the tools identified in the literature that would be specifically relevant for use in the home and community setting. Although the tools vary in terms of their involvement of consumers in the development of measures, the country in which they were developed, the scales utilized and their availability, they all have the capacity to elicit important information from clients regarding the care received.



Table 5 – Tools to measure client-centred care in the home and community sector

Title	Developed from the client perspective?	Canadian?	What does it measure?	Method of Administration	# and Type of Questions	Publicly available?
Client-Centred Rehabilitation Questionnaire (Cott et al., 2006)	Yes	Yes	Client-centredness of rehabilitation care. The questions relate to seven domains including: client participation in decision-making and goal-setting; client-centred education; evaluation of outcomes from client's perspective; family involvement; emotional support; co-ordination/continuity and physical support.	Self-administered (client)	30 items assessing client- centredness 5-point Likert scale	Yes
WASCANA Client- Centred Care Questionnaire (Cott et al., 2001)	Based upon the Picker Institute definitions of client-centred care	Yes (Rehab in Sask.)	Client-centredness of care. The questions relate to six domains including: respect and dignity; information, communication and education; physical comfort; emotional support and acknowledgement; involvement of family and friends; and integration of care.	Self-administered (client)	40 questions 5-point Likert scale	No



Table 5 – Tools to measure client-centred care in the home and community sector

Title	Developed from the client perspective?	Canadian?	What does it measure?	Method of Administration	# and Type of Questions	Publicly available?
Client-centred Care Questionnaire (Bosman et al., 2008; de Witte et al., 2006)	Yes	No	Client-centredness as experienced by clients and evaluates the effects of interventions aimed at improving the client-centredness of care and services (de Witte et al., 2006, pg. 63).	Self-administered (client)	15 questions assessing the one dimension of client- centredness 5-point Likert scale	No
The Toolkit of Instruments to Measure End of Life Care (TIME) After-Death Bereaved Family Member Interview (Teno, Claridge, Casey, Edgman- Levitan, Fowler, 2001)	Yes Built on research that identified family perspectives of 'quality' end of life care.	No	Family members' perspectives regarding the extent to which the needs/expectations of a dying person and their family were met. The questions relate to seven domains including: physical comfort and emotional support; inform and promote shared decision-making; encourage advance care planning; focus on individual; attend to the emotional and spiritual needs of the family; provide coordination of care; support the self-efficacy of the family.	Administered by staff	Varies depending on care setting Uses 10-point, 4-point and 3- point Likert rating scales, as well as yes/no and don't know response options	Yes (pending completion of a copyright agreement)



Table 5 – Tools to measure client-centred care in the home and community sector

Title	Developed from the client perspective?	Canadian?	What does it measure?	Method of Administration	# and Type of Questions	Publicly available?
The Picker Patient Experience Questionnaire (Jenkinson et al., 2002)	Yes (involved in qualitative work to define dimensions)	No	A core set of questions to measure patients' experiences that were selected from a larger set of questions developed for use in in-patient surveys to evaluate quality of care. Most questions would be relevant to the home care setting and could be adapted.	Self-administered (client)	15 questions 2-4 point scales	Yes
Home Health Care CAHPS Survey (Goldstein et al., 2005; Centers for Medicare & Medicaid Services, 2010)	Yes	No – developed and used in the U.S. for evaluation of Medicare home health services	The survey, based on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, is designed to provide information regarding consumers' perceptions of care. The home health version of the survey covers topics such as access to care, communications and interactions with agency staff.	Self-administered (mail) but can also be conducted via the telephone (client)	34 questions	The survey is available for download from the HHCAHPS survey website. All results are also reported to the public



10. CONCLUSION

This Literature Review sought to analyze the available literature examining client-centred care within the context of the home and community care sector, clarifying existing definitions, concepts and practices that can influence care in this environment. The review focused on the home and community care sector and was supplemented with literature which considered the transitions from, and between, other sites within the healthcare system. Although the focus was on the Canadian context, international examples were included to provide context or deeper understanding of information as required.

The lack of a consistent, universal definition for client-centred care and its component parts is a key challenge when examining this concept, as is the overlap and synergy between several terms which are closely related to, but distinct from, client-centred care, such as patient/family/person/relationship-centred care. The lack of an accepted definition of client-centred care has resulted in challenges regarding implementation, research into and evaluation of the phenomenon. This has resulted in a lack of clarity in what is being implemented or measured under the domain of client-centred care. Furthermore, the majority of research regarding client-centred care has been discipline-specific, making interpretation in a multidisciplinary environment (such as rehabilitation and the home and community setting) challenging. This is an area requiring further research to develop an evidence base to support interdisciplinary, client-centred care practice.

Despite the lack of an agreed upon understanding of client-centred care, the definition used for this literature review "...an approach to the planning, delivery and evaluation of home and community care that is grounded in mutually beneficial relationships and partnerships among people using the healthcare system, their family and healthcare providers," (adapted from the Institute of Patient and Family Centred Care, 2010), was reflective of many of the definitions and principles of client-centred care identified through the literature. However, upon further consultation with key experts in the area once the review was completed, the term person-centred care emerged as the most reflective of this holistic approach to healthcare, as it acknowledges the personhood of the individual outside the clinical domain. It is recommended that the term person-centred be adopted for future work in this area.

Several common components of client-centred care were identified through the literature review, including: sharing power between healthcare providers and clients; respecting clients, their views and preferences; providing information and education which is tailored to the client's needs and desire for information; communication with both clients and between healthcare providers; continuity of care, including across transition points; and involving the client in all aspects of healthcare (from the point of care to the broader systems level). Given the broad scope of this review, it was not feasible to conduct an in-depth exploration of all of these related concepts. This is a limitation, as the authors of this review acknowledge the significant amount of work which has been developed in these areas.



Although the majority of the literature examining these aspects of client-centred care in the home and community sector is based on case reports and/or qualitative investigations, which pose challenges regarding the generalizability of research findings, these methods of inquiry are considered appropriate as they are the most effective way of exploring the experience of client-centred care. They represent a key way to understand, develop and refine clinical practice aimed at tailoring service to meet needs.

The use of technology in the provision of client-centred care within the home and community care sector was also examined. Emerging technologies may dramatically change practice as they facilitate communication and access to information, and support continuity and transitions. However, serious challenges exist regarding how best to maximize the benefits from technology, implement change and measure the outcomes and impact in the complex and diffuse environment of home and community healthcare.

This literature review identified that theoretical models exist which help to describe relationships and interactions and provide structure to the provision of client-centred care. As client-centred care is not a unified construct, a multitude of approaches, models and strategies can be used to guide its use in practice. Theories from a variety of disciplines and clinical areas are available; however, there is a need to develop a theory suitable for use in a multidisciplinary environment like the home and community sector.

It was found that similar challenges exist in the implementation of client-centred care as a whole. Literature from a variety of clinical settings helped to inform the identification of potential barriers to client-centred care, ranging from those experienced at the point of care by clients and healthcare providers to systemic barriers which are negatively impacting upon attempts to integrate a client-centred approach into the broader healthcare system. Implementation strategies were identified and included recommendations which addressed a broad spectrum of interventions. Amongst these, the importance of the role that an organization plays introducing, implementing and sustaining a change in practice emerged clearly from the literature, as did the importance of leadership in facilitating a change in practice.

The importance of evaluating the presence and perceptions of client-centred care, as well as its impact using diverse approaches, including both quantitative and qualitative methodology, was an important finding of the review. As client-centred care is a multi-faceted construct, attention must be paid to proper identification of what aspect of care requires measurement and how this can be facilitated. The literature includes several examples of subjective and objective measures and assessment tools that could be used to guide the evaluation of client-centred care. It would be particularly important to build the evidence base for client-centred care practice in the home and community environment, as this was an area significantly lacking in the literature.



Two changes to our healthcare system are underway: a move from institution-based to community-based care, and growing support for a shift from a provider-centred model of care delivery to one which puts the client at the centre of healthcare. Client-centred care and how it is successfully applied in the context of home and community care could provide solutions for stakeholders who seek to develop efficient and effective models of healthcare delivery that meet the needs of all Canadians. The growing body of research and evidence regarding client-centred care will continue to provide foundations for practice as we learn more about how Canada can support a change to embrace the participation of clients at all levels of the healthcare system, so that the entire system can truly be built around each Canadian.



REFERENCES

- Abendstern, M., Reilly, S., Hughes, J., Venables, D., & Challis, D. (2006). Levels of integration and specialisation within professional community teams for people with dementia. *International Journal of Geriatric Psychiatry*, *21*(1), 77-85.
- Adams, J., & Drake, R. (2006). Shared decision-making and evidence-based practice. *Community Mental Health Journal*, 42(1), 87-105.
- Ahern, D. (2007). Challenges and opportunities of eHealth research. *American Journal of Preventive Medicine*, 32(5 Suppl), S75.
- Alakeson, V. (2010). International development in self-directed care: The Commonwealth Fund.
- Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B. (2005). The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of Health & Illness*, 27(2), 161-187.
- Atienza, A.A., Hesse, B.W., Baker, T.B., Abrams, D.B, Rimer, B.K., Croyle, R.T, Volckmann, L.N. (2007). Critical issues in eHealth research. *American Journal of Preventive Medicine*, *32*(5 Suppl), S71-S74.
- Atienza, A.A., Hesse, B.W., Gustafson, D.H., & Croyle, R.T. (2010). e-Health Research and Patient-Centered Care Examining Theory, Methods, and Application. *American Journal of Preventive Medicine*, *38*(1), 85-88.
- Ball, T. (2010). Disruptive Innovation: Patient/Family-Focused Care. Managing Change, Summer 1 16.
- Barker, P. (2001). The Tidal Model: developing an empowering, person-centred approach to recovery within psychiatric and mental health nursing. *Journal of Psychiatric and Mental Health Nursing*, 8, 233–240
- Barker, P., & Buchanan-Barker, P. (2010). The tidal model of mental health recovery and reclamation: application in acute care settings. *Issues in Mental Health Nursing*, *31*(3), 171-180.
- Barton, A. (2010). Using Mobile Health Technology to Enhance Patient-Centered Care. *Clinical Nurse Specialist*, 24(5), 233.
- Bates, D., & Bitton, A. (2010). The future of health information technology in the patient-centered medical home. *Health Affairs*, 29(4), 614.
- Bauman, A.E., Fardy, H.J., & Harris, P.G. (2003). Getting it right: why bother with patient-centred care? *Medical Journal of Australia*, *179*(5), 253-256.
- Beach, M.C., & Inui, T. (2006). Relationship centered care. *Journal of General Internal Medicine*, 21(s1), Ps3(1).



- Beach, M.C., Saha, S. & Cooper, L.A. (2006). The Role and Relationship of Cultural Competence and Patient-Centeredness in Health Care Quality, D. Lorber, (Ed.). Retrieved from:

 http://www.commonwealthfund.org/Content/Publications/Fund-Reports/2006/Oct/The-Role-and-Relationship-of-Cultural-Competence-and-Patient-Centeredness-in-Health-Care-Quality.aspx
- Beal, G., Chan, A., Chapman, S., Edgar, J., McInnis-Perry, G., Osborne, M., & Mina, E. (2007). Consumer input into standards revision: changing practice. *Journal of Psychiatric & Mental Health Nursing, 14*(1), 13-20.
- Benjamin, A.E. (2001). Consumer-directed services at home: a new model for persons with disabilities. *Health Affairs*, 20(6), 80-95.
- Berger, J.L. (2006). Incorporation of the tidal model into the interdisciplinary plan of care -- a program quality improvement project. *Journal of Psychiatric & Mental Health Nursing, 13*(4), 464-467.
- Berkman, B., Gardner, D., Zodikoff, B., & Harootyan, L. (2006). Social Work and Aging in the Emerging Health Care World. *Journal of Gerontological Social Work, 48*(1/2), 203-217.
- Bidmead, C., & Cowley, S. (2005). A concept analysis of partnership with clients. *Community Practitioner,* 78(6), 203-208.
- Boote, J., Telford, R., & Cooper, C. (2002). Consumer involvement in health research: a review and research agenda. *Health Policy*, *61*, 213–36.
- Borg, M., Karlesson, B., Tondora, J., & Davidson, L. (2009). Implementing person-centred care in psychiatric rehabilitation: What does this involve? *Israel Annals of Psychiatry and Related Disciplines, 46*(2), 84–93.
- Bosman, R., Bours, G.J., Engels, J., & de Witte, L.P. (2008). Client-centred care perceived by clients of two Dutch homecare agencies: a questionnaire survey. *International Journal of Nursing Studies, 45*(4), 518-525.
- Bournes, D. (2002). Research Evaluating Human Becoming in Practice. Nursing Science Quarterly, 15, 190-195.
- British Columbia Ministry of Health. (2007). *Primary health care charter: A collaborative approach*. Retrieved from http://www.health.gov.bc.ca/library/publications/year/2007/phc_charter.pdf.
- British Columbia Ministry of Health Services (2010). B.C. Launches Patient-Focused Funding Provincewide (News Release). Retrieved from http://www2.news.gov.bc.ca/news_releases_2009-2013/2010HSERV0020-000403.htm
- Broekhuis, M., de Blok, C., & Meijboom, B. (2009). Improving client-centred care and services: the role of front/back-office configurations. *Journal of Advanced Nursing*, *65*(5), 971-980.



- Brookman, C. (2007). The Personal Support Worker: Improving Work Experience. A Comparison Across Two Health Care Sectors. Doctoral Research. Toronto, ON: University of Toronto.
- Brown, D., McWilliam, C., & Ward-Griffin, C. (2006). Client-centred empowering partnering in nursing. *Journal of Advanced Nursing*, *53*(2), 160-168.
- Brown, S. (2003). Guest editorial: next generation telecare and its role in primary and community care. *Health & Social Care in the Community, 11*(6), 459-462.
- Bruegel, R. (1998). The increasing importance of patient empowerment and its potential effects on home health care information systems and technology. *Home Health Care Management & Practice, 10*(2), 69.
- Bruni, R.A., Laupacis, A., Martin, D.K. (2008). Public engagement in setting priorities in health care. *Canadian Medical Association Journal*, *179*(1), 15-18.
- Bu, D., Pan, E., Walker, J., Adler-Milstein, J., Kendrick, D., Hook, J., et al. (2007). Benefits of information technology—enabled diabetes management. *Diabetes Care*, *30*(5), 1137.
- Cahill, J. (1996). Patient participation: a concept analysis. Journal of Advanced Nursing, 24(3), 561-71.
- Cahill, J. (1998). Patient participation: a review of the literature. Journal of Clinical Nursing, 7(2), 119-128.
- Canadian Association of Occupational Therapists (1997). *Enabling occupation: An occupational therapy perspective*. Ottawa, ON: CAOT Publications ACE.
- Canadian Association of Occupational Therapists (1998). *Occupational therapy guidelines for client-centred practice* (Vol. 2 ed). Ottawa, Canada: Health and Welfare Canada and the Canadian Government Publishing Centre, Public Works and Government Services Canadian Association of Occupational Therapists.
- Canadian Association of Occupational Therapists (2002). *Enabling Occupation: An Occupational Therapy Perspective*. Revised edition. Ottawa, ON: CAOT Publications ACE.
- Canadian Council on Learning (2008). Health Literacy in Canada: A Healthy Understanding. Ottawa: Canadian Council on Learning.
- Canadian Home Care Association (2008). Portraits of Home Care in Canada. Retrieved from: http://www.cdnhomecare.ca/content.php?sec=9
- Canadian Home Care Human Resources Study. (2003). *Final Report*. The Home Care Sector Study Corporation. Retrieved from http://www.cdnhomecare.ca/content.php?doc=33.



- Canadian Institute for Health Information (CIHI). (2007). *Public-Sector Expenditures and Utilization of Home Care Services in Canada: Exploring the Data*. Ottawa: CIHI. Retrieved from http://secure.cihi.ca/cihiweb/products/trends_home_care_mar_2007_e.pdf
- Canadian Medical Association. (2010). *Health Care Transformations in Canada* Canadian Medical Association.

 Retrieved November 25, 2010 from

 http://www.cma.ca/multimedia/CMA/Content_Images/Inside_cma/Advocacy/HCT/HCT2010report_en.pdf
- Carrillo, J., Green, A., & Betancourt, J. (1999). Cross-cultural primary care: a patient-based approach. *Annals of Internal Medicine*, 130(10), 829-834.
- Centers for Medicare and Medicaid Services (2010). *Home Health Care CAHPS Protocols and Guidelines*Manual. Retrieved from https://www.homehealthcahps.org/Portals/0/PandGManual_NOAPPS.pdf
- Chapman, S.A., Keating, N., & Eales, J. (2003). Client-centred, community-based care for frail seniors. *Health & Social Care in the Community*, 11(3), 253-261.
- Charon, R. (2001). Narrative Medicine. *JAMA: The Journal of the American Medical Association, 286*(15), 1897-1902.
- Chow, S., Teare, G., & Basky, G. (2009). Shared decision making: Helping the system and patients make quality health care decisions. Saskatoon, SK: Saskatoon: Health Quality Council.
- Chumbler, N., Vogel, W., Garel, M., Qin, H., Kobb, R., & Ryan, P. (2005). Health services utilization of a care coordination/home-telehealth program for veterans with diabetes: a matched-cohort study. *Journal of Ambulatory Care Management*, 28(3), 230.
- Clarke, A. (2000). Using biography to enhance the nursing care of older people. *British Journal of Nursing,* 9(7), 429-433.
- Clarke, A., Hanson, E.J., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12(5), 697-706.
- Coleman, E.A., Parry, C., Chalmers, S., & Min, S.J. (2006). The care transitions intervention: results of a randomized controlled trial. *Archives of Internal Medicine*, *166*(17), 1822-1828.
- Coleman, E.A., Smith, J.D., Frank, J.C., Min, S., Parry, C., & Kramer, A.M. (2004). Preparing patients and caregivers to participate in care delivered across settings: the care transitions intervention. *Journal of the American Geriatrics Society*, *52*(11), 1817-1825.



- Community Research Planning and Evaluation Team, Community Support and Research Unit (2004). *Putting Family-Centered Care Philosophy into Practice*. Toronto, ON: Centre for Addiction and Mental Health (CAMH).
- Corring, D., & Cook, J. (1999). Client-centred care means that I am a valued human being. *Canadian Journal of Occupational Therapy*, 66(2), 71-79.
- Cott, C.A. (2004). Client-centred rehabilitation: client perspectives. *Disability & Rehabilitation, 26*(24), 1411-1422.
- Cott, C.A., Boyle, J., Fay, J., Sutton, D., Bowring, J., & Lineker, K. (2001). *Client Centred Rehabilitation*: Arthritis Community Research & Evaluation Unit (ACREU).
- Cott, C.A., Falter, L., Gignac, M. & Badley, E. (2008). Helping networks in community home care for the elderly: types of team. *Canadian Journal of Nursing Research*, 40(1), 19-37.
- Cott, C.A., Teare, G., McGilton, K.S., & Lineker, S. (2006). Reliability and construct validity of the client-centred rehabilitation questionnaire. *Disability & Rehabilitation*, 28(22), 1387-1397.
- Cott, C.A., Wiles, R., & Devitt, R. (2007). Continuity, transition and participation: Preparing clients for life in the community post-stroke. *Disability & Rehabilitation*, *29*(20-21), 1566-1574.
- Coughlin, J.F., Pope, J.E., & Leedle, Jr. B.R. (2006). Old Age, New Technology, and Future Innovations in Disease Management and Home Health Care. *Home Health Care Management & Practice, 18*(3), 196-207.
- Coulter, A. (2003). Patient information and shared decision-making in cancer care. *British Journal of Cancer,* 89, S15-S16.
- Coulter, A. (2007). Evidence on the effectiveness of strategies to improve patients' experience of cancer care. Picker Institute Europe. Retrieved from http://www.pickereurope.org/reports.
- Coulter, A., & Ellins, J. (2006). Patient-focused interventions: A review of the evidence. The Health Foundation and Picker Institute Europe.
- Cousins, A., Lee, P., Rorman, D., Raas-Rothschild, A., Banikazemi, M., Waldek, S., et al. (2008). Home-based infusion therapy for patients with Fabry disease. *British Journal of Nursing*, *17*(10), 653-657.
- Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., et al. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, *325*(7375), 1263.
- Cronin, C. (2004). Patient Centred Care: An overview of definitions and concepts: National Health Council.



- Dagnone, T. (2010). For Patients' Sake: Patient First Review Commissioner's Report to the Saskatchewan Minister of Health. Retrieved January 5, 2011, from http://www.health.gov.sk.ca/patient-first-commissioners-report
- Daykin, N., Sanidas, M., Tritter, J., Rimmer, J., & Evans, S. (2004) Developing user involvement in a UK cancer network: professionals' and users' perspectives. *Critical Public Health*, 14(3), 277–294
- de Haes, H. (2006). Dilemmas in patient centeredness and shared decision making: A case for vulnerability. *Patient Education and Counseling*, *62*(3), 291-298.
- de Witte, L., Schoot, T., & Proot, I. (2006). Development of the client-centred care questionnaire. *Journal of Advanced Nursing*, *56*(1), 62-68.
- DiLollo, A., & Favreau, C. (2010). Person-centered care and speech and language therapy. *Seminars in Speech & Language*, 31(2), 90-97.
- Doig, E., Fleming, J., Cornwell, P. L., & Kuipers, P. (2009). Qualitative exploration of a client-centered, goaldirected approach to community-based occupational therapy for adults with traumatic brain injury. American Journal of Occupational Therapy, 63(5), 559-568.
- Doucet, T., & Bournes, D.A. (2007). Review of Research Related to Parse's Theory of Human Becoming. *Nursing Science Quarterly, 20,* 16-32.
- Dow, B., Haralambous, B., Bremner, F., & Fearn, M. (2006). What is person-centred health care? A literature review. Melbourne, Victoria, Australia: National Ageing Research Institute.
- Dupuis, S., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., Sadler, L. (2010). *Moving beyond patient and client approaches: Mobilizing authentic partnerships in dementia care, support and services*.
- Edvardsson, D., & Innes, A. (2010). Measuring Person-centered Care: A Critical Comparative Review of Published Tools. *The Gerontologist*, *50*(6), 834.
- Edvardsson, D., Winblad, B., & Sandman, B. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet, 7,* 362-367.
- Eloranta, S., Arve, S., Isoaho, H., Welch, A., Viitanen, M., & Routasalo, P. (2010). Perceptions of the psychological well-being and care of older home care clients: clients and their carers. *Journal of Clinical Nursing*, 19(5-6), 847-855.
- Epp, T. (2003). Person-centred dementia care: A vision to be refined. *Canadian Alzheimer Disease Review, 5*, 14-19.



- Epstein, R., Franks, P., Fiscella, K., Shields, C., Meldrum, S., Kravitz, R., et al. (2005). Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Social Science & Medicine*, *61*(7), 1516-1528.
- Excellent Care for All Act, Legislative Assembly of Ontario, 2nd Session Sess. (2010).
- Family Services Toronto (2008). Catalyst: Ideas for Change. The Magazine of Family Service Toronto.

 Retrieved from

 http://www.familyservicetoronto.org/catalyst/catalystWinter2008/familydefinition.html
- Fletcher, E., & Stevenson, C. (2001). Launching the Tidal Model in an adult mental health programme. *Nursing Standard*, 15(49), 33-36.
- Forster, A., Murff, H., Peterson, J., Gandhi, T., & Bates, D. (2003). The incidence and severity of adverse events affecting patients after discharge from the hospital. *Annals of Internal Medicine*, *138*(3), 161-167.
- Gage, M. (1998). From independence to interdependence: creating synergistic healthcare teams. *Journal of Nursing Administration*, 28(4), 17-26.
- Gallant, M.H., Beaulieu, M.C., & Carnevale, F.A. (2002). Partnership: an analysis of the concept within the nurse–client relationship. *Journal of Advanced Nursing*, 40(2), 149-57.
- Gantert, T., & McWilliam, C. (2004). Interdisciplinary team processes within an in-home service delivery organization. *Home Health Care Services Quarterly*, *23*(3), 1-17.
- Gantert, T.W., McWilliam, C.L., Ward-Griffin, C., & Allen, N.J. (2008). The key to me: seniors' perceptions of relationship-building with in-home service providers. *Canadian Journal On Aging = La Revue Canadienne Du Vieillissement, 27*(1), 23-34.
- Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, T., & Hobbins, T. (1993). *Through the patient's eyes:* understanding and promoting patient-centered care. San Francisco, C.A.: Jossey-Bass.
- Gibson, G., Timlin, A., Curran, S., & Wattis, J. (2007). The impact of location on satisfaction with dementia services amongst people with dementia and their informal carers: a comparative evaluation of a community-based and a clinic-based memory service. *International Psychogeriatrics*, 19(2), 267-277.
- Gilbert, J. (2005). Interprofessional education for collaborative, patient-centred practice. *Nursing Leadership,* 18(2), 32-38.
- Gillespie, R., Florin, D., & Gillam, S. (2004). How is patient-centred care understood by the clinical, managerial and lay stakeholders responsible for promoting this agenda? *Health Expectations*, 7(2), 142-148.



- Glover, R. (2005). *Journey to Wellness: Designing a People-Centred Health System for Canadians*: Hushion House.
- Gold, K.S. (2007). Crossing the Quality Chasm: Creating the Ideal Patient Care Experience. *Nursing Economics*, 25(5), 293-298.
- Goldstein, E., Farquhar, M., Crofton, C., Darby, C., & Garfinkel, S. (2005). Measuring Hospital Care from the Patients' Perspective: An Overview of the CAHPS® Hospital Survey Development Process. *Health Services Research*, 40, 1977-1995.
- Goodyear-Smith, F., & Buetow, S. (2001). Power issues in the doctor-patient relationship. *Health Care Analysis*, *9*(4), 449-462.
- Government of Alberta. (2010). Government response to Alberta Health Act recommendations Retrieved Oct 31 2010, 2010, from http://alberta.ca/acn/201010/29361CAF9A2BC-C361-529B-4FEB7E1387501B9B.html
- Grant, J. (2007). The participation of mental health service users in Ontario, Canada: A Canadian application of the consumer participation questionnaire. *International Journal of Social Psychiatry*, *53*(2), 148-158.
- Grimshaw, J., Shirran, L., Thomas, R., Mowatt, G., Fraser, C., Bero, L., et al. (2001). Changing provider behavior: an overview of systematic reviews of interventions. *Medical Care, 39*(8 Suppl 2), II2-45.
- Hamalainen, P.M., Perala, M.L., Poussa, T. & Pelkonen, M. (2003). Patient participation in decision-making on the introduction of home respiratory care: who does not participate? *Health Expectations, 6*, 118-127.
- Hammell, K.W. (2001). Using qualitative research to inform the client-centred evidence-based practice of occupational therapy. *British Journal of Occupational Therapy*, *64*(5), 228-234.
- Health Canada (2002). Canada Health Act Overview. Retrieved November, 2010, from http://web.archive.org/web/20071217093738/http://hc-sc.gc.ca/ahc-asc/media/nr-cp/2002/2002_care-soinsbk4_e.html
- Health Canada (2004a). *Home Care in Canada 1999: An overview*. Ottawa, Ontario. Retrieved from: http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/1999-home-domicile/index-eng.php
- Health Canada (2004b). Home and Community Care. *Health Canada's Role*. Retrieved from: http://www.hc-sc.gc.ca/hcs-sss/home-domicile/commun/index-eng.php
- Henderson, S. (2002). Influences on patient participation and decision-making in care. *Prof Nurse*, *17*(9), 521-525.



- Hesse, B., & Shneiderman, B. (2007). eHealth research from the user's perspective. *American Journal of Preventive Medicine*, *32*(5 Suppl), S97.
- Hobbs, J.L. (2009). A dimensional analysis of patient-centered care. Nursing Research, 58(1), 52-62.
- Holyoke, P. (2010). Keeping the 'home' in home care: Phase 1 findings [unpublished manuscript].
- Hook, M.L. (2006). Partnering with patients a concept ready for action. *Journal of Advanced Nursing*, *56*(2), 133–143.
- Huvane, K. (2008). Points of care. As the home care industry continues to expand, technology must connect caregivers to home base. *Healthcare informatics: the business magazine for information and communication systems*, *25*(5), 34.
- The Institute for Patient- and Family-Centred Care. (29 December 2010). Frequently Asked Questions. Retrieved June 2010, from http://www.ipfcc.org/faq.html
- Jacob, J., Holmes, D., & Buus, N. (2008). Humanism in forensic psychiatry: the use of the tidal nursing model. *Nursing Inquiry*, 15(3), 224-230.
- Jenkinson, C., Coulter, A. & Bruster, S. (2002). The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *International Journal for Quality in Health Care*, *14*(5), 353-358.
- Jenner, E.A. (1998). A case study analysis of nurses' roles, education and training needs associated with patient-focused care. *Journal of Advanced Nursing*, *27*(5), 1087-1095.
- Jerant, A., Azari, R., Martinez, C., & Nesbitt, T. (2003). A randomized trial of telenursing to reduce hospitalization for heart failure: patient-centered outcomes and nursing indicators. *Home Health Care Services Quarterly*, 22(1), 1-20.
- Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S.E., Sodomka, P.I., Schlucter, J., & Ford, D. (2008). Partnering with patients and families to design a patient- and family- centred health care system: Recommendations and promising practices. Retrieved from: http://www.ipfcc.org/pdf/PartneringwithPatientsandFamilies.pdf
- Jönsson, A., & Willman, A. (2008). Implementation of Telenursing within Home Healthcare. *Telemedicine and e-Health*, 14(10), 1057-1062.
- Kane, R.A., Degenholtz, H.B & Kane, R.L. (1999). Adding values: An experiment in systematic attention to values and preferences of community long-term care clients. *The Journals of Gerontology: Series B: Psychological sciences and social sciences, 54B*(2), S109.



- Kibbe, D. (2009). Toward a modular EHR. Family Practice Management, 16(4), 8-9.
- Kitwood, T. (1997). Dementia reconsidered: the person comes first. Buckingham: Open University Press.
- Kuziemsky, C., Borycki, E., Purkis, M., Black, F., Boyle, M., Cloutier-Fisher, D., et al. (2009). An interdisciplinary team communication framework and its application to healthcare 'e-teams' systems design. *BMC Medical Informatics and Decision Making*, *9*(1), 43.
- Ladd, R.E., Pasquerella, L., & Smith, S. (2000). What to do when the end is near: Ethical issues in home care nursing. *Public Health Nursing*, *17*(2), 103–110.
- Legault, F., & Ferguson-Pare, M. (1999). Advancing nursing practice: an evaluation study of Parse's theory of human becoming. *Canadian Journal of Nursing Leadership, 12*(1), 30-35.
- Leonhardt, K.K., Bonin, D., & Pagel, P. (2006). Partners in safety: Implementing a community-based patient safety advisory council. *Wisconsin Medical Journal*, 105(8), 54-59.
- Lévesque, L., Ducharme, F., Caron, C., Hanson, E., Magnusson, L., Nolan, J., & Nolan, M. (2010). A partnership approach to service needs assessment with family caregivers of an aging relative living at home: A qualitative analysis of the experiences of caregivers and practitioners. *International Journal of Nursing Studies*, *47*(7), 876-887.
- Levin, R. & Herbert, M. (2001). Delivering health care services in the community: A multidisciplinary perspective. *Social Work in Health Care*, *34*(1-2), 89-99
- Lewis, S. (2009). Making Patient Centered Care Real: The Road to Implementation. A Discussion Paper for the Saskatchewan Ministry of Health: Access Consulting Ltd.
- Lindsay, E. (2006). Leg Clubs: giving patients a voice in leg ulcer management. *Community Practitioner, 79*(8), 245-246.
- Litchfield, R., & MacDougall, C. (2002). Professional issues for physiotherapists in family-centred and community-based settings. *Australian Journal of Physiotherapy*, 48(2), 105-112.
- Livermore, P. (2003). Teaching home administration of sub-cutaneous methotrexate. *Paediatric Nursing*, 15(3), 28-32.
- Local Health Integration Networks. (2010, 12/02/2010). About LHINs. Retrieved from http://www.lhins.on.ca/aboutlhin.aspx?ekmensel=e2f22c9a_72_184_btnlink
- Lutz, B., Chumbler, N., Lyles, T., Hoffman, N., & Kobb, R. (2009). Testing a home-telehealth programme for US veterans recovering from stroke and their family caregivers. *Disability & Rehabilitation, 31*(5), 402-409.



- MacAdam, M. (2004). Examining home care in other countries: the policy issues. *Home Health Care Management & Practice*, *16*(5), 393-404.
- MacLellan, D., & Berenbaum S. (2007). Canadian Dietitians' Understanding of the Client-Centered Approach to Nutrition Counseling. *Journal of the American Dietetic Association*, 107(8), 1414.
- MacLellan, D. L., & Berenbaum, S. (2006). Dietitians' opinions and experiences of client-centred nutrition counselling. *Canadian Journal of Dietetic Practice and Research*, *67*(3), 119-124.
- Magnusson, A., & Lützén, K. (1999). Intrusion into patient privacy: a moral concern in the home care of persons with chronic mental illness. *Nursing Ethics*, *6*(5), 399-410.
- Magnusson, A., Severinsson, E., & Lützén, K. (2003). Reconstructing mental health nursing in home care. *Journal of Advanced Nursing*, 43(4), 351-359.
- Maitra, K., & Erway, F. (2006). Perceptions of Client Centred practice in Occupational Therapists and their clients. *The American Journal of Occupational Therapy, 60*(3).
- McCormack, B. (2003). A conceptual framework for person-centred practice with older people. *International Journal of Nursing Practice*, *9*(3), 202-209.
- McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing*, 13(3a), 31-38.
- McCormack, J.P., & Loewen, P. (2007). Adding "value" to clinical practice guidelines. *Canadian Family Physician*, *53*(8), 1326-1327.
- McGarry, J. (2009). Defining roles, relationships, boundaries and participation between elderly people and nurses within the home: an ethnographic study. *Health & Social Care in the Community*, 17(1), 83-91.
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, *5*(2), 148-158.
- McWilliam, C.L. (2009). Patients, persons or partners? Involving those with chronic disease in their care. *Chronic Illness*, *5*(4), 277-292.
- McWilliam, C.L., Coleman, S., Melito, C., Sweetland, D., Saidak, J., Smit, J., et al. (2003). Building empowering partnerships for interprofessional care. *Journal of Interprofessional Care*, *17*(4), 363 376.
- McWilliam, C.L. Kothari, A., Kloseck, M., Ward-Griffin, C., Forbes, D. (2008a). Organizational learning for evidence-based practice: a "PAKT" for success. *Journal of Change Management*, 8(3-4), 233-247.



- McWilliam, C.L., Kothari, A., Leipert, B., Ward-Griffin, C., Forbes, D., King, M., et al. (2008b). Accelerating Client-Driven Care: Pilot Study for a Social Interaction Approach to Knowledge Translation. *Canadian Journal of Nursing Research*, 40, 58-74.
- McWilliam, C.L., Stewart, M., Brown, J.B., McNair, S., Desai, K., Patterson, M.L. et al. (1997). Creating empowering meaning: An interactive process of promoting health with chronically ill older Canadians. *Health Promotion International*, 12(2), 111-123.
- McWilliam, C., Stewart, M., Brown, J., McNair, S., Donner, A., Desai, K., et al. (1999). Home-based health promotion for chronically ill older persons: results of a randomized controlled trial of a critical reflection approach. *Health Promotion International*, *14*(1), 27-41.
- McWilliam, C. L., Stewart, M., Vingilis, E., Hoch, J., Donner, A., Browne, G., et al. (2004). Flexible client-driven in-home case management: An option to consider. *Care Management Journals*, *5*(2), 73-86.
- McWilliam, C.L., Stewart, M., Vingilis, E., Ward-Griffiin, C., Donner, A., Anderson, K., Hoch, J., et al. (2007). Can we afford consumer choice in home care? *Care Management Journals*, 8(4), 171-179.
- McWilliam, C.L., Ward-Griffin, C., Sweetland, D., Sutherland, C., & O'Halloran, L. (2001). The experience of empowerment in in-home services delivery. *Home Health Care Serv Q, 20*(4), 49-71.
- Mead, N., & Bower, P. (2000a). Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science & Medicine*, *51*(7), 1087-1110.
- Mead, N., & Bower, P. (2000b). Measuring patient-centredness: a comparison of three observation-based instruments. *Patient Education & Counseling*, *39*(1), 71-80.
- Millard, L., Hallett, C., & Luker, K. (2006). Nurse-patient interaction and decision-making in care: patient involvement in community nursing. *Journal of Advanced Nursing*, *55*(2), 142-150.
- Mitchell, G. J., Bournes, D. A., & Hollett, J. (2006). Human becoming—guided patient centered care: New perspectives transform nursing practice. *Nursing Science Quarterly*, 19, 218-224.
- Mitchell, G., Closson, T., Coulis, N., Flint, F., Gray, B. (2000). Patient-focused care and human becoming thought: Connecting the right stuff. *Nursing Science Quarterly, 13,* 216-224
- Mitcheson, J., & Cowley, S. (2003). Empowerment or control? An analysis of the extent to which client participation is enabled during health visitor/client interactions using a structured health needs assessment tool. *International Journal of Nursing Studies, 40*(4), 413-426.
- Moore, L., & Wasson, J. (2006). An introduction to technology for patient-centered, collaborative care. *Journal of Ambulatory Care Management, 29*(3), 195.



- Morgan, P.A., & Moffatt, C.J. (2008). Non healing leg ulcers and the nurse–patient relationship. Part 2: the nurse's perspective. *International Wound Journal*, *5*(2), 332–339.
- Mowbray, C.T., Woodward, A.T., Holter, M.C., MacFarlane, P., & Bybee, D. (2009). Characteristics of users of consumer-run drop-in centers versus clubhouses. *Journal of Behavioral Health Services & Research*, 36(3), 361-371.
- Nilsen, E.S., Myrhaug, H.T., Johansen, M., Oliver, S., & Oxman, A.D. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews, 3*, CD004563.
- Nolan, M., Davies, S., & Brown, J. (2006). Transitions in care homes: towards relationship-centred care using the 'Senses Framework'. *Quality in Ageing*, 7(3), 5-14.
- Nolan, M.R., Brown, J., Davies, S., Nolan, J. and Keady, J. (2006). The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No 2. Project Report. University of Sheffield.
- Nolan, M.R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, *13*(3a), 45-53.
- Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a more inclusive vision of dementia care practice and research. *Dementia* (14713012), 1(2), 193-211.
- Norris, W.M., Wenrich, M.D., Nielsen, E.L., Treece, P.D., Jackson, J.C., Curtis, J.R. (2005). Communication about end-of-life care between language-discordant patients and clinicians: insights from medical interpreters. *Journal of Palliative Medicine*, *8*(5): 1016-24.
- O'Connor, A., Stacey, D., Entwistle, V., Llewllyn-Thomas, H., Rovner, D., Holmes-Rovner, M., et al. (2009). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews, 3*. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub2
- Ontario Medical Association. (2010). Policy paper Patient Centred Care. Ontario Medical Review.
- Ontario Ministry of Health and Long-Term Care (2010). Ontario's Aging at Home Strategy. Retrieved from http://www.health.gov.on.ca/english/public/program/ltc/33_ontario_strategy.html.
- Ottmann, G., Laragy, C., & Haddon, M. (2009). Experiences of disability consumer-directed care users in Australia: results from a longitudinal qualitative study. *Health & Social Care in the Community*, *17*(5), 466-475.
- Oudshoorn, A., Ward-Griffin, C., & McWilliam, C. (2007). Client-nurse relationships in home-based palliative care: a critical analysis of power relations. *Journal of Clinical Nursing*, *16*(8), 1435-1443.



- Pan-Canadian Planning Committee on Unregulated Health Workers (2008). Valuing Health-Care Team Members: Working with Unregulated Health Workers. Ottawa: CNA.
- Parry, C., Coleman, E.A., Smith, J.D., Frank, J., & Kramer, A.M. (2003). The care transitions intervention: a patient-centered approach to ensuring effective transfers between sites of geriatric care. *Home Health Care Services Quarterly*, 22(3), 1-17.
- Parry, C., Kramer, H.M., & Coleman, E.A. (2006). A qualitative exploration of a patient-centered coaching intervention to improve care transitions in chronically ill older adults. *Home Health Care Services Quarterly*, 25(3-4), 39-53.
- Parse, R. (1992). Human becoming: Parse's theory of nursing. Nursing Science Quarterly, 5(1), 35.
- Pateman, B., Wilson, K., McHugh, G., & Luker, K.A. (2003). Continuing care after cancer treatment. *Journal of Advanced Nursing*, 44(2), 192–199
- Pedlar, A., Hornibrook, T., & Haasen, B. (2001). Patient focused care: theory and practice. *Therapeutic Recreation Journal*, 35(1), 15-30.
- Pelzang, R. (2010). Time to learn: understanding patient-centred care. *British Journal of Nursing, 19*(14), 912-917.
- Pivik, J.R. (2002). *Practical strategies for facilitating meaningful citizen involvement in health planning. Discussion Paper 23*. Commission on the Future of Health Care in Canada. Retrieved from: http://dsp-psd.pwgsc.gc.ca/Collection/CP32-79-23-2002E.pdf
- Ponte, P.R., Conlin, G., Conway, J.B., Grant, S., Medeiros, C., Nies, J., et al. (2003). Making patient-centered care come alive: Achieving full integration of the patient's perspective. *Journal of Nursing Administration*, 33(2), 82-90.
- Province of New Brunswick. (2008). *Transforming New Brunswick's Health-care System: The Provincial Health Plan 2008-2012*. Retrieved from http://www.gnb.ca/cnb/promos/php/PHP-e.pdf.
- Rahimi, B., Vimarlund, V., & Timpka, T. (2009). Health information system implementation: A qualitative meta-analysis. *Journal of Medical Systems*, *33*, 359-368.
- Reid, D., Angus, J., McKeever, P., & Miller, K.L. (2003). Home is where their wheels are: experiences of women wheelchair users. *American Journal of Occupational Therapy*, *57*(2), 186-95.
- Registered Nurses Association of Ontario. (2002). Nursing Best Practice Guideline: Client Centred Care.

 Toronto, Canada: The Registered Nurses Association of Ontario.



- Registered Nurses Association of Ontario. (2006). Nursing Best Practice Guideline: Client Centred Care: Supplement. Toronto, Canada: The Registered Nurses Association of Ontario.
- Restall, G., & Ripat, J. (2008). Applicability and clinical utility of the Client-Centred Strategies Framework. *Canadian Journal of Occupational Therapy, 75*(5), 288-300.
- Restall, G., Ripat, J., & Stern, M. (2003). A framework of strategies for client-centred practice. *Canadian Journal of Occupational Therapy Revue Canadienne d'Ergotherapie, 70*(2), 103-112.
- Restall, G., & Strutt, C. (2008). Participation in planning and evaluating mental health services: building capacity. *Psychiatric Rehabilitation Journal*, *31*(3), 234-238
- Rivadeneyra, R., Elderkin-Thompson, V., Cohen Silver, R., & Waitzkin, H. (2000). Patient centeredness in medical encounters requiring an Interpreter. *American Journal of Medicine*, 108(6), 470-4
- Robinson, J.H., Callister, L.C., Berry, J.A., & Dearing, K.A. (2008). Patient-centered care and adherence: definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners*, 20(12), 600-607.
- Rogers, A., Kennedy, A., Nelson, E., & Robinson, A. (2005). Uncovering the limits of patient-centeredness: implementing a self-management trial for chronic illness. *Qualitative Health Research*, 15(2), 224-239.
- Romanow, R. (2002). *Building on values: the future of health care in Canada. Final Report.* Ottawa: Commission on the Future of Health Care in Canada.
- Rootman, I. & Gordon-El-Bihbety, D. (2008). A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy. Ottawa, ON: Canadian Public Health Association.
- Rosenthal, T. (2008). The Medical Home: Growing Evidence to Support a New Approach to Primary Care. Journal of the American Board of Family Medicine, 21(5), 427-440.
- Ross, L., & Johansen, C. (2002). Psychosocial home visits in cancer treatment: a qualitative study on the content of home visits. *Cancer Nursing*, *25*(5), 350.
- Rosser, W., Colwill, J., Kasperski, J., & Wilson, L. (2010). Patient-centered medical homes in Ontario. *New England Journal of Medicine*, *362*(3), e7.
- Roush, C.V., & Cox, J.E. (2000). The meaning of home: how it shapes the practice of home and hospice care. Home Healthcare Nurse, 18(6): 388-94.
- Russo, H. (2001). Window of opportunity for home care nurses: Telehealth technologies. *Online Journal of Issues in Nursing*, 6(3), 1-16.



- Schoot, T., Hirsch, M., & de Witte, L. (2007). Development of competencies aimed at client-centred care: an evaluation study. *Learning in Health & Social Care*, 6(2), 104-117.
- Schoot, T., Proot, I., Legius, M., Meulen, R.T., & de Witte, L. (2006). Client-centered home care: balancing between competing responsibilities. *Clinical Nursing Research*, *15*(4), 231-254.
- Schoot, T., Proot, I., Meulen, R.T., & de Witte, L. (2005a). Actual interaction and client centeredness in home care. *Clinical Nursing Research*, *14*(4), 370-393.
- Schoot, T., Proot, I., Meulen, R.T., & de Witte, L. (2005b). Recognition of client values as a basis for tailored care: the view of Dutch expert patients and family caregivers. *Scandinavian Journal of Caring Sciences*, *19*(2), 169-176.
- Sepucha, K.R., Fowler Jr, F.J., & Mulley Jr, A.G. (2004). Policy support for patient-centered care: The need for measurable improvements in decision quality. *Health Affairs*, *23*(SUPPL), VAR-54-VAR-62.
- Sevin, C., Moore, G., Shepherd, J., Jacobs, T., & Hupke, C. (2009). Transforming care teams to provide the best possible patient-centered, collaborative care. *Journal of Ambulatory Care Management*, 32(1), 24-31.
- Shaller, D. (2007). Patient centered care: what does it take? Retrieved from http://www.commonwealthfund.org/~/media/Files/Publications/Fund%20Report/2007/Oct/Patient %20Centered%20Care%20%20What%20Does%20It%20Take/Shaller_patient%20centeredcarewhatd oesittake_1067%20pdf.pdf
- Sheridan, J.E. (1992). Organizational culture and employee retention. *Academy of Management Journal,* 35(5), 1036-1056.
- Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: a review of qualitative studies. *Journal of Clinical Nursing*, 15(10), 1317-1323.
- Sidani, S., Epstein, D., & Miranda, J. (2006). Eliciting patient treatment preferences: A strategy to integrate evidence-based and patient-centered care. *Worldviews on Evidence-Based Nursing*, *3*(3), 116-123.
- Silow-Carroll, S., Alteras, T., & Stepnick, L. (2006). *Patient-Centered Care for Underserved Populations:*Definition and Best Practices. Washington, DC: Economic and Social Research Institute.
- Slasberg, C. (2010). Can personalisation be a reality for older people? *Working with Older People: Community Care Policy & Practice*, 14(3), 15-22.
- Sommers, L.S., Marton, K.I., Barbaccia, J.C., & Randolph, J. (2000). Physician, nurse, and social worker collaboration in primary care for chronically ill seniors. *Archives of Internal Medicine*, *160*(12), 1825-1833.



- South Australian Department of Public Health. (2000). *Improving Health Services Through Consumer Participation: A Resource Guide For Organisations*: Department of Health and Ageing.
- Spiers, J.A. (2002). The Interpersonal Contexts of Negotiating Care in Home Care Nurse-Patient Interactions. *Qualitative Health Research*, 12(8), 1033-1057
- Spragins, W., & Lorenzetti, D. (2008). *Public Expectation and Patient Experience of Integration of Health Care:*A Literature Review. Toronto: The Change Foundation.
- Stevens, B., McKeever, P., Law, M., Booth, M., Greenberg, M., Daub, S., Gafni, A., Gammon, J., Yamada, J., Epstein, I. (2006). Children receiving chemotherapy at home: Perceptions of children and parents. *Journal of Pediatric Oncology Nursing*, 23(5), 276-285.
- Stewart, M., Brown, J.B., Donner, A., McWhinney, I.R., Oates, J., Weston, W.W., Jordan, J. (2000). The impact of patient-centered care on outcomes. *Journal of Family Practice*, *49*(9), 805-807.
- Stewart, M., Brown, J.B., Weston, W.W., McWhinney, I.R., McWilliam, C.L., Freeman, T.R. (2003). *Patient-centered medicine: transforming the clinical method* (2nd ed.). Abingdon, U.K.: Radcliffe Medical Press.
- Sumsion, T. (2004). Pursuing the Client's Goals Really Paid Off. *British Journal of Occupational Therapy, 67*(1), 1-9.
- Sumsion, T. (2005). Facilitating client-centred practice: insights from clients. *Canadian Journal of Occupational Therapy*, 72(1), 13-20.
- Sumsion, T. (Ed). (2006). Client-Centred Practice in Occupational Therapy: A Guide to Implementation (2nd ed.). New York: Churchill Livingstone/Elsevier.
- Sumsion, T., & Law, M. (2006). A review of evidence on the conceptual elements informing client-centred practice. *Canadian Journal of Occupational Therapy Revue Canadienne d'Ergotherapie, 73*(3), 153-162.
- Sumsion, T., & Lencucha, R. (2009). Therapists' perceptions of how teamwork influences client-centred practice. *British Journal of Occupational Therapy, 72*(2), 48-54.
- Sumsion, T., & Smyth, G. (2000). Barriers to client-centredness and their resolution. *Canadian Journal of Occupational Therapy*, 67(1), 15-21.
- Teno, J.M., Claridge, B., Casey, V., Edgman-Levitan, S., & Fowler, J. (2001). Validation of Toolkit After-Death Bereaved Family Member Interview. *Journal of Pain & Symptom Management, 22*(3), 752-758.



- The King's Fund (2010). How to deliver high-quality, patient-centred, cost-effective care: Consensus solutions from the voluntary sector. Retrieved from:

 http://www.kingsfund.org.uk/publications/articles/how_to_deliver.html.
- Themessl-Huber, M., Hubbard, G., & Munro, P. (2007). Frail older people's experiences and use of health and social care services. *Journal of Nursing Management*, 15(2), 222-229.
- Tobin, M., Chen, L., & Leathley, C. (2002). Consumer participation in mental health services: who wants it and why? *Australian Health Review*, *25*(3), 91-100.
- Tresolini, C.P. and the Pew-Fetzer Task Force. (1994). Health Professions Education and Relationship-centered Care. San Francisco, CA: Pew Health Professions Commission.
- Tritter, J.Q. & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy, 76,* 156–168.
- U.S. Department of Health and Human Services (2011). About Health Literacy. Retrieved from http://www.hrsa.gov/publichealth/healthliteracy/healthlitabout.html
- von Koch, L., Wottrich, A.W., & Holmqvist, L.W. (1998). Rehabilitation in the home versus the hospital: the importance of context. *Disability & Rehabilitation*, *20*(10), 367-372.
- Walker, J., & Carayon, P. (2009). From tasks to processes: the case for changing health information technology to improve health care. *Health Affairs*, 28(2), 467.
- Walters, B., Barnard, D., & Paris, S. (2006). Patient portals" and "E-visits. *The Journal of Ambulatory Care Management*, 29(3), 222-224.
- Wasson, J., & Baker, N. (2009). Balanced Measures for Patient-Centered Care. *The Journal of Ambulatory Care Management*, 32(1), 44-55.
- Wilkins, S., Pollock, N., Rochon, S., & Law, M. (2001). Implementing client-centred practice: why is it so difficult to do? *Canadian Journal of Occupational Therapy Revue Canadienne d'Ergotherapie, 68*(2), 70-79.
- Wilson, P.M. (2008). The UK Expert Patients Program: Lessons learned and implications for cancer survivors' self-care support programs. *Journal of Cancer Survivorship, 2*(1), 45-52.
- Woodward, C.A., Abelson, J., Tedford, S., & Hutchison, B. (2004). What is important to continuity in home care? Perspectives of key stakeholders. *Social Science & Medicine*, *58*, 177-92.
- World Health Organization (1978). *Alma-Ata: Primary Health Care "Health for all"*, Series, No 1. WHO, Geneva.



- World Health Organization (WHO).). (1998). *Health Promotion Glossary*. Division of Health Promotion, Education and Communications (HPR) and Health Education and Health Promotion Unit (HEP), Geneva: Switzerland. Retrieved from: http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf
- Wottrich, A., von Koch, L., & Tham, K. (2007). The meaning of rehabilitation in the home environment after acute stroke from the perspective of a multiprofessional team. *Physical Therapy*, 87(6), 778–788.
- Wressle, E., & Samuelsson, K. (2004). Barriers and bridges to client-centred occupational therapy in Sweden. Scandinavian Journal of Occupational Therapy, 11(1), 12-16.
- Wright, C., & Rowe, N. (2005). Protecting professional identities: service user involvement and occupational therapy. *British Journal of Occupational Therapy*, *68*(1), 45-47.
- Wylie, J.L., & Wagenfeld-Heintz, E. (2004). Development of relationship-centered care. *Journal for Healthcare Quality: Promoting Excellence in Healthcare*, 26(1), 14.
- Young, A.S., Chinman, M., Forquer, S.L., Knight, E.L., Vogel, H., Miller, A., Rowe, M., & Mintz, J. (2005). Use of a consumer-led intervention to improve provider competencies. *Psychiatric Services*, 56 (8), 967-75.



Please provide us with feedback on this report by completing this brief, 5-minute survey:

http://www.surveymonkey.com/s/BRCR3D7